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# Enculturating empathy: the ethical representation of institutional review boards

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# ENCULTURATING EMPATHY: THE ETHICAL REPRESENTATION OF INSTITUTIONAL REVIEW BOARDS

by

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## DEDICATION

This work is dedicated to my loving and patient family, partner, and the study participants who helped me engage with these research questions.

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**ENCULTURATING EMPATHY: THE ETHICAL REPRESENTATION OF INSTITUTIONAL REVIEW BOARDS**

**CATHERINE MCCARTHY**

ABSTRACT

As part of a preliminary literature review of research concerning the relationship between medical anthropology and bioethics committees, it became clear that Institutional Review Boards, a foundational component of research, had never been evaluated as a population with a characterizable identity. Some examples of contextual critiques and policy analysis with the goal of procedural efficiency were accessible (Gunsalus 2006; Fitzgerald 2009; Lederman 2006; Ozdemir 2009; Sontag 2012), but qualitative data on the local knowledge of IRBs as a population do not exist.

A synthesis of theoretical orientations and methodological planning have been integrated to inform these novel research questions to learn more about the ethical decision-making process of an Institutional Review Board within a research university and hospital. Bioethical reasoning grounded in Western morals creates enough opportunity for cognitive dissonance because of the potential misapplication of ethics, but when decision-making authority is deemed objectively scientific, it can cause a power dynamic by being taken as self-evident. Considering these biomedical frameworks, research with human subjects is grounded in morality, making IRBs a relevant site of praxis for philosophical and scientific research.

The overall purpose of this project is to identify the ethical values that define Institutional Review Boards as a population, evaluate the moral implications of

biomedical governmentality in clinical research, and define common phenomenological understandings of moral praxis within positions of relative power.

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## LIST OF ABBREVIATIONS

BU ..... Boston University

BUMC ..... Boston University Medical Campus

BMC ..... Boston Medical Center

IRB ..... Institutional Review Board

# INTRODUCTION

## Research Questions

There is a morning in March 2020 where I can't taste my coffee anymore. It doesn't register at first—I start to think I have the flu. I could taste the sweet mixed with the bitter, but nothing else. I couldn't find the "coffee" taste at all. It was like the connection stopped somewhere between the back of my tongue and what I knew it was *supposed* to taste like.

A month later, the coronavirus has fully infiltrated the United States and like other urban areas, Boston, Massachusetts becomes a central hub of infection and a destitute preview of the impending pandemic. When I take the MBTA (the T, or train) to get groceries downtown, I start to notice people covering their faces with scarves and bandanas. Anything at first.

A woman stops me as we walk by closed store fronts. She asks us for money and as we slow down, she pulls her mask down and tells us her mother has just died of COVID and she needs help getting out of town. I feel the fear grow in me, I can't help it. There was a genuine terror around it at first—the unknown. None of us knew what we were dealing with. We pull away quickly, and she yells after us.

When I attend my Internship with the Institutional Review Board, I admit that I was hopeful to get some sort of insider knowledge as to what kind of research was at the forefront of tackling the pandemic. Though I did not understand a lot of the more scientific language, it was reassuring to know that things were happening and in good hands.

I noticed that I was not the only one keen for new information. Every time I logged into Zoom for a "Panel Meeting," I was met with conversations between members about the impact of the virus. Some people worried out loud, others shared personal grievances, and others still went on with their lives as if nothing was happening. The diversity of circumstances was interesting—and also reflected the reality of life for the heavily stratified population of Boston. While some people mourned loved ones they could not bury, others went on vacation.

That being said, my original reservations about this group of individuals being a good representation of Boston was further complicated.

When I first learned of the Institutional Review Board, I was immediately intrigued with its structural make-up. There are ethics boards for most important institutional decisions, and the concept of a small number of people chosen to represent the population is, in my opinion, anthropologically fascinating. When it specifically comes to medical research, are there certain voices that need to be represented? What *kind* of people can dictate what makes ethical experiments? And what makes those people ethical? Is it certain decision-making credentials? Maybe some common experiences? What makes someone a good *enough* representative to have moral authority?

From an anthropological perspective, representation is a difficult thing to articulate. Even more difficult is attempting to categorize people without limiting or labelling them in doing so. So how can representation then be ethically done? I argue that it takes a conceptual understanding of anthropological insight when it comes to culturally informed values and further, a new paradigm of ethical pluralism. Before arguing more for this

anthropologically informed perspective of ethics, the bioethics still enforced and contrived out of the inveterate inception of Institutional Review Boards must be wholly understood.

**The Conception of Current Bioethics**

On November 25th, 1945, honorable Justice Robert H. Jackson presided over the International Military Tribunal in Nuremberg, Germany. In his commanding opening statement, Jackson addresses the "twenty-odd broken men" who committed these "crimes against humanity" and states, "It is hard now to perceive in these men as captives the power by which as Nazi leaders they once dominated much of the world and terrified most of it. Merely as individuals their fate is of little consequence to the world," he scathingly attests. "What makes this inquest significant is that these prisoners represent sinister influences that will lurk in the world long after their bodies have returned to dust," (Jackson, 1945).

He goes on to make the striking point: "Civilization can afford no compromise with the social forces which would gain renewed strength if we deal ambiguously or indecisively with the men in whom those forces now precariously survive." (Jackson, 1945).

Following this grand opening statement, Judge Jackson indicted 24 Nazi officials and 6 organizations for counts of: The Common Plan or conspiracy, Crimes Against Peace, War Crimes, and Crimes Against Humanity. According to the Robert H. Jackson Center, only 21 of these defendants appeared in court. One was elderly and in failing

health, one was tried in absentia, and one committed suicide on the eve of the trial (Jackson, 1945).

According to his personal notes of the event, Jackson contemplated, “The speech seemed an important task to me because up to that time no one had disclosed to the world what the case really amounted to, what the evidence was and what law we were contending for.” He continued, “The speech also seemed to have important public consequences because it would be the first full disclosure of the materials that we had captured and had at hand, and of the use we attempted to make of them” (The Reminiscences of Robert H. Jackson Columbia Univ. Oral History Research Office, 1955, Pages 1390-1392; Jackson, 1945).

This trial was the first public demonstration of the “crimes against humanity” designed and perpetrated by German scientists during World War II. The world watched in horror as the extent of experiments and harm done was read to the international council. Judge Robert H. Jackson noted this in his statement, remarkably able to understand and contend with this imperative turn in the history of humanitarianism.

It is important for people to know what happened—the whole truth, no matter how deviant or ugly. Jackson knew this, he knew it mattered for the future of science, even humanity. It was not swept under the rug or played down at all. The experiments were (consensually) deemed unethical.

In retrospect, we along with every other country involved came up with the concept of informed consent and voluntary participation when it came to scientific or medical research. Though we can hope this had mostly been an intuitive concept before,

it was now put into bureaucratic writing and secularly enforced. Following this international display, the United States must then realize the cruelty of its own Tuskegee experiments at home, and the values of "respect for persons, beneficence, and justice" became similarly ingrained in the conception of American bioethics with the publishing of the Belmont Report (Grady 2015, 1150).

These "ethical principles" are still used as a standard by the IRB today, even to the point of having them printed on sheets of paper for each Panel Meeting I attended, as well as a framed final reminder of the three values near the door. Oddly, this repetitiveness of principles often reminded me of something from a church or religious service.

I wondered how such broad generalizations could be interpreted the same, especially with a board of people attempting to promote diversity of review. This is how I came to final articulations of my research questions: do institutions of moral authority, like the IRB, enculturate their own ethical values? What is the process of reconciling individual understandings of institutionally enforced values? Finally, what actually makes an "ethical person" in the context of the IRB, and how do they think of themselves?

The joint Institutional Review Board at Boston Medical Center and Boston University was gracious enough to let me participant in, and observe, their meetings and to speak with their members in a collaborative attempt to find out.

**Gap and Importance**

Though Institutional Review Boards have existed since the publishing of the Belmont Report, not much research has been done on its existence as a population or on its individual characteristics. While different IRBs exist at all federally funded institutions conducting research on human subjects, each of their Panels are diverse and held to a general recruiting standard put forth by the US Office of Human Research Protections. Comparative research between IRB populations is still to be done. Beyond some procedural critiques and general theory on aspects of working under increasing institutional stress (Gunsalas et al. 2006, Lederman 2006), IRBs have yet to be considered as a population for biomedical or anthropological research, much less one of representational, societal, and moral authority. In contrast, there is still important and necessary research needed on scientific institutions' relationships and engagements with their respective communities.

Further, and as extrapolated upon in the Chapter Four (*Ethical Pluralism*) of this thesis, anthropology is a way of understanding and categorically evaluating different ethical values as reflections and shapers of cultural systems. In the last decade of anthropological thought, there have been many new ways of attempting to talk about and categorize morality. Though it has been historically separated from philosophical theory and language, Signe Howell (1997b) notes, "It might be argued that anthropologists have, ultimately, always been studying the variety of social constructions of morality with a more or less explicit aim of eliciting premises for comparative ethics" (Howell 1997, 6; quoted in Mattingly and Throop 2018, 1).

In “The Anthropology of Ethics and Morality,” (2018) Cheryl Mattingly and Jason Throop provide an excellent summary of this historical engagement and recent fluctuation of the ethical in anthropological thought. They trace the foundations to ethnographic engagements with “ethical dimensions of social life” found in Marrett (1902, 1931) and Malinowski (1926, 1929, 1936) to Evans-Pritchard (1937). In the twentieth century, they note a “subsequent spattering of philosophically engaged ethnographic writings,” and then a larger contribution on “the *problem* of moral emotions and personhood” (my emphasis) in the 1970s and 1980s. Finally, these theories paved the way for phenomenological writings in the 1990s that “arose in the context of medical, religious, and psychological anthropological research on individual-, family-, and community-level responses to affliction, suffering, violence, trauma, and pain” (Mattingly and Throop 2018, 477). As Mattingly and Throop observe, this complicated relationship with ethics may reveal the “dominant Western conceptions of moral life: its commonsense models of morality” (Mattingly and Throop 2018, 477). In other words, because of anthropology’s early construction of the ethical with Western epistemology, it has been difficult to conceptualize, much less claim any objective theory within the field.

“From its earliest days, anthropology has been in a complex, ambivalent, and at times explicitly adversarial relationship with philosophy” (Mattingly & Throop 2018, 477). In the last decade, however, anthropology has engaged with much more interdisciplinary discourse. Along with philosophy, aspects of linguistics, history, sociology and especially psychology have been brought into this longstanding conversation of morality. While this “ethical turn” in anthropological thought has

cultivated new and prominent theories, there still seems to be some ethnographic framework missing. How do we identify and categorize these values? Are there universal notions of good and bad, understood by different names? We can begin by identifying *places* of moral decision-making. In these places of power, or representational authority, notions of morality are named.

This project attempts to define a consensus of bioethical values by examining an Institutional Review Board at a prominent research university. Though comparative studies are further needed, the goal of this study is to both draw attention to places of relative power as a form of 'moral authority' and provide a framework of pluralistic and comparative ethics to better integrate the insights of ethics and medical anthropology.

**Goals and Review of Methodology**

When I initially began this project, I wanted to learn how doctors' personal values influenced their medical and research decisions. Further, I wanted to learn how these ethical values were integrated into their biomedical practices. Upon living and researching in Boston, it became clear that this might be apparent in the city's terrible opioid epidemic that is heavily influenced by its history of structural oppression and harsh economic divide. Instead of narrowly focusing on such stigma, which rightfully constitutes its own volume of work, I was introduced to the Institutional Review Board as a part of understanding the methodology of research design, and I was immediately captivated by its interdisciplinary aims.

The methodology of this research was fundamentally changed by the onset of COVID-19. Because of this timing, my research was able to incorporate both its chronological repercussions and individual prominence to these theories. In this regard, I was able to experience a paramount and ethically questionable period in the context of medical research. I was also able to speak to more study participants because of the access and comprehensibility granted by Zoom on both an individual and Panel level. In the end, while the pandemic drastically affected this research, I believe it underscored the impact and important aspects of a cultural crisis as well.

To that effect, I was able to complete the internship portion of this project with the IRB in person, and began collecting data with the same group of people online. I conducted participant-observations of Panel Meetings for Panel Blue, Green, and Orange via Zoom. I was also able to complete individual interviews with multiple members of all panels and representing all roles. Finally, I recruited for a Focus Group of Boston-area IRB staff and coincidentally spoke with individuals in similar leadership positions from different institutions.

**Conclusion**

In all, this study was designed to identify, define, and cohesively evaluate the ethical values that IRBs may exhibit as a population. In completing the thematic and further anthropological analysis of this data, it became clear that individuals interpret their experiences in whatever ethical framework they are given. Through the process of "narrative-thinking" (Cheryl Mattingly 1998) and the "objective self-fashioning" (Joseph

Dumit 1997) of ethics, people understand and further incorporate ethical meaning within their own framework of learned values and experiences. In other words, this experiential reasoning with subjective ethics and notions of morality influence how people further navigate their worlds.

Using the bioethical frameworks provided by the IRB, individuals tasked with moral reasoning and authority must represent many perspectives and diverse vantage points while also engaging with study participants who represent equally diverse cultural frames of reference. The current challenge is how to reflect this kind of pluralism in the ethical analyses and assessment of research design and further institutional decision-making. In the following chapters, this study will elaborate on what I call an "*ethical pluralism*" as a solution to this challenge and the "problem of ethics" anthropologists now face (Laidlaw 2002).

# BACKGROUND

## A Social History of Boston

When I first arrived in Boston, it reminded me of Houston, Texas. Though the older, beautifully preserved architecture boldly stands alongside modern compared to Houston's widespread construction of "industrial suburbs", you can immediately tell that this is another port city. Not in a calm-sea-breeze way, but in its cavalier movement of people, culture, and products that ignites kinetic energy and reminds me of why a revolution started here. New York may be the city that never sleeps, but Boston has a constant chaotic vigor that's hard to not get swept up in. It's why there are famous mob riots whether the Red Sox win or lose and you can count on people to generally have your back and call out anyone who acts like a jerk in public. The loyalty and genuine attitude of people reminded me of friends I made in Houston, but there is a stronger sense of community here that I did not expect for such a big city.

Before long, I learned that this energy is the defining perseverance that has allowed generations to survive in Boston. The "southern charm" that I grew up with now seems superficial and detached, but also shows a history of naïve privilege. In living and researching here, I learned that authentic concern and cooperation often comes out of living in suffering together. Also known as "biosociality" (Paul Rabinow, 1996), those who experience some affliction together as a community become stronger in identifying with it and *each other*.

This energy has become a product of Boston's culture. I felt the same attitude of resilience in Houston, but in Boston, this liveliness was somehow louder, maybe angrier.

In Texas and most of the south, most of the population has ancestral roots—generations of stories and quiet endurance that permeate the earth, stain it, and grow outward. In comparison, Boston's ever-changing population does not reflect its foundational proprietors—it's a constant movement of working and living and scraping by that fit perfectly together in a complex machine. Where Houston has preserved its roots, Boston has built stubborn community.

In spite of this, there is a low-hum suffering that can be felt in the disparity between the populations that work and live here. As with other growing metropolitan areas, rent prices are continuously climbing with the demand for space. Finding work and other hardships are exacerbated by the competition between students and faculty attending Boston's incredible list of prestigious universities at the cost of minority communities being pushed out while their jobs stay inside the inner city (Vrabel, 2014; Jennings 2016; Preis et al. 2020). Gentrification exists as a threat in any fluctuating city economy, but these circumstances create higher rates of poverty and suffering that are bound to result in individuals seeking relief by any means possible. While there are avenues of support for the growing Boston community, individuals may not seek them out for various reasons including access, knowledge, or fear of embarrassment.

As a pristine example, Boston Medical Center and Boston University Medical Campus is located in the city's recently invigorated (*gentrified*) South End neighborhood, nestled between the newly coined "SoWa" district (after the famous "SoHo", New York) and Massachusetts Ave, one of the main throughways into and out of south Boston. This growing neighborhood is a mix of overpriced boutique thrift shops and families

struggling to get by. As more people are being pushed out to make room for those who can afford it, the growing homeless population and commonplace agony has also made Boston a horrific example of the American opioid epidemic (Boston Globe: Methadone Mile; Boston Globe 2016).

Between historic rows of brownstones occupied by Puerto Rican families and young professionals attending Boston Medical Center, the corner of "Mass Ave" and Albany St. was identifiable and undeniable on my first visit to my new graduate school. Grimly nicknamed "Methadone Mile" by the hospital security, this stretch of intersection showcases some of the most undignified and disturbing images of human desperation that most will never have to come to terms with. In the Netflix docuseries, "Dope" (2019), Methadone Mile is showcased in the episode titled, "The Devil's Oldest Trick," where the filmmakers explain the lasting effects and cyclical victimization of the War on Drugs in urban sprawls (Season 3, Episode 1).

This infamous side of Boston is where Boston Medical Center and Boston University has historically treated and educated generations of the surrounding communities.

**History of Boston Medical Center**

The New England Female Medical College (previously referred to as Boston Female Medical College) became the first institution to train women in medicine in 1848 (BUMC History). In 1872, the "Great Fire" destroyed buildings in the business districts of Boston, greatly affecting the NEFMC's goals of raising money to become aligned with

Harvard University (BUSM Timeline). In 1873, Boston University "assumed responsibility" of the College and it was renamed Boston University School of Medicine, becoming the first accredited coed medical school in the United States (BUSM) (BUMC History). Throughout its history, BUSM has committed itself to servicing society and has maintained a reputation of being one of the best academic research institutions in the US. Even today, *US News & World Report* lists Boston University as tied for #29 in Best Medical Research Schools in the nation for 2021 (*US News & World Report* 2021).

In a similar history, the Massachusetts Homeopathic Hospital (MHH) opened and became one of the first endowed research institutions of its time in 1855. Although technically a separate institution, MHH goes through many name changes and eventually becomes the Boston University Medical Center Hospital (BUMCH) which is later combined with Boston University School of Medicine to form Boston University Medical Center (BUMC) in 1962 (BUMC History; BUSM Timeline). In 1864, Boston City Hospital finished construction in Boston's "South End" neighborhood and became the first municipal hospital in the US (BUMC History). As a public hospital, it was established for use by "the worthy poor who are citizens of Boston" (Cheever, David W. 1906, 16).

Over the next few decades, BCH served the Boston public and incorporated more of a focus on research through the specific support and establishment of the Thorndike Memorial Laboratory and the Finland Laboratory for Infectious Disease (BUMC History). In 1973, Boston University assumed professional and clinical responsibility of

Boston City Hospital and these research laboratories, "concluding the relationships of BCH with Harvard and Tufts medical schools" (BUSM Timeline).

As Boston University's School of Medicine develops, it continues to establish groundbreaking departments for innovative teaching and research. In July 1996, Boston City Hospital merged with BUMCH to form a singular Boston Medical Center, a "not-for-profit institution that fully retains the missions and commitments of its predecessor institutions" (BUMC History). With a consistent institutional focus on both research and serving the "worthy poor" of South Boston, the Institutional Review Board at Boston Medical Center is a foundational and often paradoxical entity of protecting human subjects in exploratory medicine.

**Institutional Review Boards**

When I was still going to in-person IRB meetings, I always wore my best jewelry. A December 5th, 2019 entry from my fieldnotes journal states after messy bullet points, "*Put on my gold jewelry today*" followed by, "*Who am I trying to impress? With wealth? Prestige*?" Finally, "*Will I be taken more seriously*?" (5 December 2019, Panel Green).

I remember favoring pearl earrings and my "Aggie" class ring from Texas A&M University. I wanted to be seen as someone with a college degree, like I was *supposed* to be there--or at least fit in with everyone else. Before knowing what an IRB was fully responsible for, I knew that it would be composed of talented, respected faculty whom I felt as though I needed to impress. Everyone on the board was gracious and

unquestioning of my visitation during the first few meetings. I fit the look and demeanor of an intern amongst scientists and professors.

Institutional Review Boards are responsible for the oversight of biomedical research decisions involving human subjects at all federally funded institutions in the United States. This includes academic systems, hospitals, and prisons. Independent review of clinical research by an IRB or equivalent body "is required for US studies funded by the Department of Health and Human Services (DHHS) and other US federal agencies, as well as for research testing interventions—such as drugs, biologics, and devices—that are under the jurisdiction of the US Food and Drug Administration (FDA)" (Grady 2015, 1148). The primary purpose of an IRB is to protect human subjects participating in research. In addition, and secondary to this, Institutional Review Boards ethically approve research proposals, train investigators and internally monitor clinical researchers for any potential bias or conflicts of interest (Grady 2015, 1148-1149).

Conceptually, IRBs positively contribute to the necessary institutional oversight of research guidance. Ethics seem inherent to a system that is focused on exploring the possibilities of biomedicine for the betterment of humanity, but its conception has a notably immoral history. Though protecting human subjects is a good and necessary part of scientific research, the principles of beneficence and justice were only realized retrospectively.

*History of IRBs*

During World War II, Nazi doctors experimented on the innocent prisoners of concentration camps in what the rest of the world would later refer to as "crimes against humanity" (Mariner 2019). During the 1946 Nuremburg Trials in which the doctors were convicted, the honorable Justice Jackson stated, "The wrongs which we seek to condemn and punish have been so calculated, so malignant, and so devastating that civilization cannot tolerate their being ignored because it cannot survive their being repeated" (Mariner 2019). The experiments committed in "the name of science" and showcased during the Nuremberg Trials introduced biomedical research and war crimes on a global stage (Mariner 2019). This public realization of a cross-cultural crisis and subsequent reorientation of ethical principles could possibly be considered what anthropologist Jarrett Zigon has called a "moral breakdown" in his ethnographic research. This concept theorizes that certain events force actors to separate themselves from their everyday, largely unreflective *habitus* in order to evaluate themselves and the ethical dilemma at hand in a more self-conscious way (Zigon 2007, 135). His reading of Bourdieu's *habitus* and Martin Heidegger's "being-in-the-world" follows that an actor's embodied moral dispositions are never fully encapsulated or complete, but open to more orientations or understandings of ethics as moral dilemmas arise.

Following the public convictions, the Nuremburg Code was established in 1979 with intentions of becoming internationally recognized and implemented ethics in research (Devine 2019). It is the first advocacy for such concepts of informed consent and voluntary participation, though nothing was written into law at the time.

While fighting for human rights abroad, the United States Public Health Service was quietly conducting its infamous Tuskegee experiments on impoverished African American men with syphilis to determine the morbidity of the disease (Devine 2019). Once identified as having contracted the infection, the men were never informed of a diagnosis or treated in any way. This study took place between 1932 and 1972, running for 40 years after penicillin became the effective treatment in 1947 (CDC). In 1972, the *New York Times* published an article on the study, causing public uproar. Under mounting public pressure over the outrage of direct treatment prevention, the study finally ended with 74 of its original 600 subjects (Brandt 1978, 21). When the ethics were ultimately questioned, the CDC and AMA still backed the importance of the research (Devine 2019).

Two years after the Tuskegee study ended, the Department of Health and Human Services issued 45 CFR 46, which "included a requirement for group ethics review and the term 'institutional review board' was introduced" (Grady 2015, 1150). Following this, the US congress created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, which became the later framework for a modern IRB review system (Grady 2015, 1150). Upon the realization of Tuskegee and the widespread failure to follow guidance established in the Nuremberg Code, the Commission drafts the Belmont Report in 1979 (Devine 2019). This report, and successive "Belmont principles" was published and "incorporated into updated US regulations in 1981" (Grady 2015, 1150). After this, "the 1981 DHHS regulations were subsequently adopted by 16 federal agencies in 1991 as the Common Rule," not

including the FDA, which had previously required an IRB since 1981 (Grady 2015, 1150).

The Belmont Report distinguishes procedural methodology between research and clinical practice (*and the outlining for the misconception of the two*), and establishes three principles for conducting ethical biomedicine that is still used today. "The federal mandates were clear: any research involving human subjects funded by a Department agency, with certain exemptions, must be evaluated by an Institutional Review Board (IRB)," that considers *respect for persons*, *beneficence*, and *justice* in their evaluation of scientific practice (Marshall 2003, 51).

*Organization of IRBs*

In regular compliance with the DHHS Office of Human Research Protections, all federally funded research institutions must have an Institutional Review Board. "Most research institutions, universities, and health-care facilities have at least one IRB, and the majority have more than one" (Grady 2015, 1150). A foundational component of the research process, not much is required about its overall institutional structure of core staff. There is generally an administrative team of IRB Analysts and a Director that provide the framework and logistical support between researchers and institutional officials. In addition to this first line of inquiry, boards of "Panel Members" are appointed to designated cohorts for group discussion and review of particular research. These boards vary by institution and meet dependent on the amount of studies funded within their medical or research jurisdiction.

These Panel Members are usually experts in various fields and are responsible for the overview and assurance of ethical guidelines for research subjects as well as contributing their specialized knowledge when necessary. Following the general guidelines enforced by the OHRP, Boston Medical Center and Boston University Medical School have their IRB composition requirements listed in their Human Research Protection Program Policies on their website:

> "The IRB boards have at least five members with varying backgrounds to promote complete and adequate review of the research conducted at Boston Medical Center and Boston University Medical Campus. Members come from multiple professions, diverse cultural backgrounds, and both genders."

In my experience of the boards, this was always true. I was almost relieved by the amount of diversity represented, though I would not say it was representative of the BMC patient population. Half of the board was always female, most of them being white. The men were mostly white as well, but showed more range in ages. The Medical Doctors were mostly men while the women had other more specific departmental roles or knowledge. The policy continues:

> "The IRB includes members with knowledge of institutional commitments and requirements, the local community, local research, local context, and experience with subjects likely to be vulnerable to coercion or undue influence, such as children, prisoners, individuals with impaired decision-making capacity, or economically or educationally disadvantaged persons,"

Making specific note to an "experience with" vulnerable people, this line indicates the need for a community representative on each board. Standard language allows for each respective IRB to determine what this means for their community. Alongside the medical expertise, community members are expected to hold various roles or specialties on the board. If a Panel needs additional knowledge about the specific perspective of a study, like research with prisoners, they will call in an additional representative. At BMC, there was also a someone present from the institutional domestic violence program that was considered a scientist role.

In my research, the community members that I was able to speak with were all recruited through some other institutional pathway. In doing so, they all had some previous knowledge or experience with research without being from the scientist or researching perspective. They were often much easier to get ahold of and usually spoke highly of their time on the board compared to their busier counterparts. The blurb goes on:

> "At least one member of the IRB is a nursing representative who is a Boston Medical Center Educator/Professional Registered Nurse. At least one member of each IRB board is a scientist, at least one member is a non-scientist, and at least one member is unaffiliated. Members are considered non-scientists when their primary professions or areas of interest are in nonscientific areas,"

Even with a quorum of 6 members needed to start the Panel Meeting, the requirements are clearly bureaucratically structured to represent a diverse constituency. There are specific indications to incorporate all perspectives of the research process, with broad

enough language for individual IRBs to make their own community accommodations. The last condition states:

> "Members are considered unaffiliated when neither they nor any immediate family member is an employee or student at Boston Medical Center or Boston University. Unaffiliated members are considered to represent the perspective of research participants,"

I did not speak with many unaffiliated community members, and it seemed that very few were present. Their inclusion as the perspective of potential research participants is interesting, as it seems that most research subjects are recruited from outside of the institution and rather from its surrounding communities. Finally,

> "According to quorum requirements (see Section 5.6), at least one non-scientist must be present at each meeting. The expectation is that at least 75% of meetings will have one or more unaffiliated members present" (OHRP Policies).

The composition of all these professionals was rather intimidating at first. Though there were sometimes other young visiting physicians or researchers, it was clear that I stuck out in IRB meetings because of my age. I was obviously there as a visitor or intern and did not quite have the experience or research knowledge to provide any discussion, but I blended in enough to fade into the background and observe.

I had my pearl earrings, and my class ring, and my journal, so I quietly sat back into this new role.

**Interacting Moral Registers within Bioethics**

While individuals may often indicate an overarching and ambiguous ethical worldview, there are frequently sharp internal tensions or even contradictions in the ethical reasoning and decision-making deliberations that take place in the course of people's everyday lives. Such tensions or discontinuities in "style" may be especially pronounced among individuals who inhabit or otherwise acts in different social domains, or what the German sociologist Max Weber referred to as "value domains" (Weber 1946). Anthropologists of morality in recent years have begun to explore the ways in which individuals may negotiate these different ethical styles or "registers," both at the level of society and in their personal lives.

Samuli Schielke addresses these "moral registers" and relative identity fragmentation in his fieldwork with young Muslim men during Ramadan. Schielke explains that during the holy month, certain behaviors have an increased sense of social and moral significance as well as strict religious obligations. "Ramadan is 'the season of worship' (mûsim al-'îbâda), a time when people try to be good – that is, observe religious commandments and moral virtues more rigorously than they usually do" (Schielke 2009, S27). The perceived ambivalence of ethics between one context to the next is clear in his portrayal of youth decision-making. While these young men generally share the same understanding of religious commandments, their interpretation and practice were vastly different in their everyday life. Through this fieldwork, Schielke found that, "morality is not a coherent system, but an incoherent and unsystematic conglomerate of different

moral registers that exist in parallel and often contradict each other" (Schielke 2009, S30).

As expressed by these young men during Ramadan, individuals who inhabit or are obligated to different moral registers must often navigate between them in determining their personal ethics. Schielke identifies the most common interacting registers for his population, each within realms of societal and personal expectations and informed by an individual's certain life experience. These are institutionally recognized and culturally dependent, including aspects of religion, family and community, love, and development of the self. This ambiguous, pluralistic conception of morality is thus accompanied by "declaredly amoral aims and strategies that people deem necessary to fill the 'emptiness' of the everyday and to reach material well-being," (Schielke 2009, S31). In other words, people often make contradictory ethical decisions when faced with different situational circumstances and potentially as they learn more about the world they inhabit. Thus, individuals navigating between or across different value spheres characterized by different moral registers may understand and engage ethical dilemmas in manners that show some degree of "carry over" from one domain and one register to another.

Within an IRB setting, where bioethical reasoning is supposed to be explicit, Panel Members engage in less formal ways, *across* different registers through the sharing of narrative and personal experiences. This subsequent ethical plurality exemplifies a complex web of interacting moral registers within modern bioethics. Additionally, while the relative demographic of each panel is intentionally structured for diverse decision-making, not all moral registers represented have sufficient authority by institutional

standards. There is an inevitable plurality in the interpretation of highly standardized reasoning and judgement authorized by institutions like the IRB, but there is second notable dimension of interest that has to do with how people weigh their own ethical experiences. For these reasons, anthropologists of morality have tasked themselves with understanding how institutions marked by pronounced social hierarchies and power differentials may also influence the moral registers deployed and the ethical enculturation that takes place in different value spheres.

**The Process of Enculturation**

In 1970, anthropologist Nobuo Shimahara defined enculturation as "a bipolar process of cultural transmission and transmutation operating on the pre-adult and adult levels of human growth" (Shimahara 1970, 143). Frustrated with a lack of consensus on the theory, she wrote of the distinction from socialization as being far more conceptual, abstract, and objectified than observable human behavior. She maintained that although enculturation is an immaterial cultural theory, the action of such involves ritual change. In other words, "a process of enculturation, therefore, involves a behavioral, interactional level," that is an internalized transmission between two cultures. (Shimahara 144).

Noting Melville Herskovitz' (1964) biological contribution to the theory, the author articulates enculturation as a seemingly adaptive cultural conditioning (Shimahara 144). Building off Herskovitz' conceptualization, Shimahara states, "enculturation is in large measure viewed as the unconscious process of learning carried on before one reaches maturity and as the mechanism for the stabilization of culture" (Shimahara 144).

Consciously, enculturation takes place through choice and agency. Therefore, the interaction of enculturation at an unconscious and conscious level provides the framework for adaptive change.

Shimaharma argues that in postmodernity, reorientation or reorganization of the self takes place throughout an individual's lifetime, usually with the formation of a unique individual personality that hopefully begins at the onset of adulthood (Shimahara 147). Drawing upon psychological theories of: "V. C. Flugel, H. A. Murray, Christine Morgan, M. B. Smith, J. S. Bruner, R. W. White," and most prominently, "[Daniel Levinson (1964)] regards the formation of ideology as an external function of the ego--a means by which the individual structures his social reality, guides his behavior, and searches for the meaning of his life" (Shimahara 147).

Therefore, the rules that individuals live by--however articulated and meaningful--occurs as a dynamic transmission throughout different contexts and narratives. These "psychodynamics of personality," or moral groundings […], "allows for 'important new developments and partial restructurings,' by means of which ideological change takes place in the personality structure, 'throughout life,' although the relative durability and consistency of personality structure is determined around the age of five or six" (Levinson 1964, 310; Shimahara 1970, 147).

In normal human development, children begin to create a sense of "self" and "other" within their first few years of life. Reasoning about consequences and action thus closely follows a recognition of agency. William Hurlbut, a Stanford bioethicist and neurobiologist, states, "Moral thinking is inherent in the development of human

consciousness, for as the self becomes aware of other selves, the ethical issue inescapably arises as to how one person should treat another. (Hurlbut 2002, 12).

Like a transaction or "conversation" (Hurlbut), culture is not simply imprinted upon a person; it is a negotiation between a reasonable agent and their environment. Shimaharma aptly concludes that "in brief, the personality structure of an individual is not the internalization of the culture into which he is born," but the conscious negotiations they have with meaning (Shimahara 147). Following this theory, it can be said that enculturation can take place at any point in individual's lifetime, as long as they are conscious of it.

Human beings are unique in their sentimental value. The ability to reason with the abstract is what sets us apart from nature, or so we think. "Whereas most creatures live in a continuous immediacy of life, humans have the freedom to pull the past into the present through learning stored as memory and the freedom to pull the future into the present through the creative imagination" (Hurlbut 2002, 16). The creation of culture is our human legacy through time. It is the creation and perpetuation of life by our means and at our ends. Relativist prescriptions aside, human beings are a product of progressive evolution that in theory should drive us to flourish. Our innate human ability to reason with history sets a precedent to be better because of it. So, are we getting better?

# METHODS

## Introduction

The purpose of this study is to identify, define, and theorize on the ethical values that research ethics committees exemplify as culturally distinct populations. By analyzing common conceptions of moral foundations in biomedicine, this study evaluates the use of different ethical frameworks from within relative positions of power. The further aim of this research was to understand how institutionally representative "moral people" value themselves and their decisions within their personal worldviews.

From June through August of 2020, I conducted in-depth interviews with full time Panel Members and select staff of the Institutional Review Board (IRB) responsible for the oversight of research conducted by Boston University Medical School and Boston Medical Center. This IRB and other federally funded research institutions must consist of specialized Panels consisting of at least 5 board members from different specialties who provide expert knowledge and differing research perspectives. Anthropological methods of participant observation were used to gather data on group dynamics and ethical discussions that were later coded using thematic analysis to conceptualize an overarching trend of limitless progress and hope in Western bioethics. Finally, I conducted a focus group with Boston-area IRB analysts and leadership to better understand institutional variances and collective aims in research protection for human subjects.

Though some research exists to critique IRB procedures and evaluation methods, in contrast, this study is the first to consider the population of decision-makers as an entity in itself with definable characteristics and value systems. In addition to this gap in

biomedical literature, understanding the cultural aspects of moral decision-making is an important and paradigm shifting aspect of modern anthropological research.

**Process**

I started with a general question about bias in medicine. First, I wanted to know if someone's personal experiences changed the way they made health decisions for others. This initially led me to look at experiences of suffering in often stereotyped and criminalized populations of illegal drug users. Beyond this question of addiction medicine and its growing knowledge of social determinants, I wanted to also understand how race played a role in access and further defined the patient-physician relationship.

During the first few weeks of graduate school, I was able to explore Boston and learn more about its rich, tumultuous cultural history. In living and going to school in the South End, I also became immediately aware of Boston's continuing opioid epidemic and its foundation of structural violence against the suffering of *vulnerable* people (POC, LBGTQ+, immigrant and low-income families). As I began to design my research project, I came to the realization that even if I could talk to physicians who treated these *vulnerable* people and prove some sort of bias, *then what*? I already knew there was stigma because *I felt it*. So how could an institution commit to "Exceptional service without exception," while aiding a community plagued with institutionally sanctioned suffering? Instead of continuing to highlight the population dynamic, I wanted to understand how objective people dealt with their biases and how to address it in influencing medical decision-making for communities.

In learning about the research process that my program's cohort and I would be undergoing, the Institutional Review Board quickly became an important part of understanding any research design in an academic institution. The idea of an ethical committee consisting of different medical (and some non-medical) experts to discuss and approve the purpose of scientific research was undoubtedly the perfect place to ask my developing research questions pertaining to moral influence. More to the point, I would be able to more clearly see how bioethical decisions were made and carried out in protecting human subjects. In contrast to further depicting a desperate community that I felt was vilified enough, I would be able to understand why and how strangers came to make medical decisions *for the sake* of others.

**The Population**

Before starting graduate school, I had not heard of "Institutional Review Boards". Although I studied anthropology at another research institution for my undergraduate degree, I had not had the opportunity of working closely with any research process. I assumed that an ethics committee would be involved at some point, but was unsure of the purpose or decision-making capacities and was curious to how people were chosen for such a role.

I have grown up around academia. Both of my parents have worked for universities my entire life and I have been around faculty enough to fit in or at least realize its sociological boundaries and gatekept cultural knowledge. In other words, I feel comfortable enough there and I understand the etiquette. Its quietly hierarchical and each

university has a *habitus* of its own (Bourdieu 1977). Beyond academic prestige, as with most Western institutions, its objective is increasingly capitalistic (Heller 2016). Therefore, the financial history of universities usually details where its values persist. In terms of Boston University and specifically Boston University Medical Campus, $865 million is highlighted for research awards anticipated in 2019 on the university website (BUMC Research). Boasting one of the most prominent medical research campuses in the nation, BUMC produces both exploratory and treatment-focused biomedical science that further develops the field of healthcare in various specialties.

In the federal process of Human Subjects Research, studies must be sent to and approved by an institutions' IRB or equivalent entity to both objectively condone the purpose of research and evaluate whether it consistently meets all ethical requirements set by the US Office of Human Research Protections (OHRP). In addition to IRB Analysts who serve as a first-line of communication and research design staff to aid researchers in improving the logistics of their studies, panels of experts meet by institutional guidance in order to discuss (usually 'non-exempt') research studies for the assurance of human subjects' protection within their medical communities. These Panel Members are experts in various specialties and are responsible for the overview and assurance of ethical guidelines for research subjects as well as contributing their expert knowledge in their respective fields when necessary. Separated into different boards of around five to fifteen members each, BUMC has their IRB composition requirements listed in their Human Research Protection Program Policies on their website and discussed at length in the background chapter.

My population sample was originally limited to the 20 active and participating members of Panel Blue and Panel Green as registered with the Office of Human Research Protections, as well as certain observed reoccurring alternates during the 2019-2020 IRB cycle. At the advice of the IRB Director, I sampled Panels Blue and Green because of their relevance with human subjects and domestic studies. When I submitted of the IRB proposal for this research, it was decided to include Panel Orange for further recruitment and participant-observation. Senior IRB Analysts and the IRB Director form another sample of this population. In communicating with researchers and Panel Members, guiding study designs, and educating investigators, analysts provide another perspective of applied group dynamics. The Director provides extensive administrative overview and supervision of the IRB**.**

**The Field Site**

The IRB Office is incredibly hard to get to for being such a prominent component of research. Though I do not think they chose to be hidden away, most of their communications with researchers takes place online and through a mandated system like INSPIR to ensure an audit trail of sorts. After getting into the Medical Campus and past security with an ID badge, you have to take multiple turns to find a specific set of elevators that open onto the back corridor of one of the research buildings. If a meeting with the IRB is needed, as it was when I first started my internship, they will gladly send you exact directions to get there and then apologize for the absurdity of it. As I continued

to observe through this research, this characteristic humble mediation would become a theme at the foundation of the institution.

I do not remember the office itself being special in any way. It was on the fourth floor, so the view was as nice as any in downtown Boston, and the blinds were always up in order to gaze upon the never-ceasing dreariness. When you enter from the corridor, you go beyond two stuck-open hallway doors and come to an opening with a closed off conference room on your right and the administrative secretary typing furiously at a desk to your left. They will stop you before you can go any further, but behind their desk and down the hall are the offices of the IRB analysts, director, and tech specialist as well as a second, smaller conference room and kitchen. It is not a receptionist desk, so they will not smile, but plainly ask, "How can I help you?" in order to prevent any disturbance to the growing workload of the offices around them.

My Service Learning Internship, or my graduate program's "SLIP" site, predominantly took place in the main conference room to the immediate right of the IRB office where Panel Meetings occurred every Thursday afternoon from 12:00 to 2:00PM. At one end of the room was a full countertop and kitchen sink where lunch would be provided by catering at every meeting – always complete with cookies or some other dessert. On the other end of the room was a 70-inch monitor industrially plated to the middle of the wall and intended to display study details on INSPIR (the internal communication and research processing platform) for individuals in the meeting to follow along. In the middle, there was a long conference table that could sit up to 18 people as well as chairs along both sides of the room intended for any guests or visitors. I

attempted to sit in the back corner of the conference room any time I observed in order to be able to evaluate the physical components and positionality of subjects in the room. Before long, this became my unclaimed, personally-claimed spot for observing and I noticed that anytime I had to move due to someone else, I would immediately feel uncomfortable and less focused on my notes. I noticed that other people had usual spots too, and sometimes they even spoke less if they had to move for whatever reason. The IRB analysts always sat together near the monitor, and the director moved from this in-group to the opposite side of the table intermittently. The Chairs, or Panel Leaders, tended to sit toward the middle and captivated the room without much energy. As soon the meeting would begin to commence, whether due to time or halt in small talk, the body language in the room would immediately all point inward toward this person at the table. Though all the Chairs are men, the panels are relatively proportionate in sex and gender (about 4:6) and seating is further evidence of this difference in members. The women tended to sit with each other on one end of the room, with the same outliers each time.

Chatting took place at the beginning of each meeting, usually pertaining to the catering that week or veracity of the cold that day, sometimes even asking about a member's children or grandchildren. Most of the professionals have worked together in the IRB or BU/BMC for years. They know one another from departmental meetings and fundraising events. Unaffiliated members are less privy to the institutional culture, but seem to hold their own in incumbency within the board. At the end of each meeting, some would stay behind to finish their outside conversations or see if there were any leftover sodas and treats. The director would stay behind and answer any questions for

more curious members and usually start to clean up the lunch remains with the rest of the IRB staff, who would then serve themselves if they were not at the meeting. To uphold standards of transparency, I informed the remaining IRB Staff of this developing study during a department meeting in February of 2020 where a preliminary research recruitment flyer was dispersed. I began this internship in November and attended Panel Meetings as an intern until I was approved for research in early June. The last in-person meeting I attended was on March 5th, 2020, as the coronavirus was steadily making its way through Boston, specifically in respect to the massive Biogen Conference in Massachusetts the week prior, we were all seemingly unaware of the impending threat to us and the rest of American population (BioGen Conference).

**Planning and Recruitment**

The scratch fieldnotes that I have from March 5th 2020 only mention the virus briefly. They state in bullet points, "*Coronavirus talk before meeting starts*" and later, "*Less people than last meeting, wonder if related to COVID-19*?" After this week, the university had spring recess and we would not return back to campus.

As people continued to succumb to a disease worldwide that we knew little information about, most Americans were watching Wuhan, China in fear as the chaos unfolded from afar until February 29th, when a man died from the virus in Seattle, Washington, marking that it was already here and spreading. On March 12th, Boston University Medical Campus officials announced that all in-person human research must stop. According to the New York Time's timeline of the pandemic, the president declared

the coronavirus a national emergency on March 13th, and the CDC then recommends no gatherings of 50 or more people on March 15th, prompting academic institutions to close their doors soon after and prepare for online instruction (NYT Covid Timeline).

March, April, and May proved to be extremely difficult for urban areas and dense populations as the coronavirus circulated throughout the northeast. Images from New York mirrored Boston on a larger scale. Everyone was terrified--you could feel it in the air. It was a more feral response to the panic back then, and it truly felt bleak. We did not know anything about this thing that was killing our neighbors. We still do not understand it, but in the beginning, we did not even know how it made people so sick--we kept our heads down and expected the worst. This is when I became sick too.

Although it first felt as if I was battling a seasonal cold, I did not feel I was at risk for the coronavirus until one morning when I noticed that my coffee tasted incredibly bland. Within a week, I had lost all capability of taste and smell and could barely get out of bed. My back ached like the depths of my lungs were sore. I could only stay awake for an average of five hours before getting a debilitating migraine. It was hard to move; it felt like I was slowly turning to stone. More than anything, I was terrified of what was to come - was this a death sentence? In March, I was scared to get tested in fear of picking up the virus if I did not already have it. By April, I tested negatively; but the damage to Boston, and by chance my body, had been done.

Despite the turmoil brewing, some research and scientists went into hyperdrive at Boston University. Though in-person research was prohibited, Principal Investigators (PIs) quickly reimagined their projects for a virtual platform at the guidance of the IRB

and Office of Human Research Affairs. What was once going to be dependent on the context of a professional environment would now need to be facilitated through audio and video in the privacy of someone's home. Zoom appeared as the consistent software and IRBs requested that study teams think about including alternate plans in any research submissions.

In my proposals, I knew that I wanted to conduct semi-structured interviews with Panel Members. I wanted to have a conversation with open-ended questions that would allow them to both tell their story and think about their placement among their peers. Initially, I thought this would most likely take place at their convenience and wherever possible (most likely their offices) due to how busy they all seem. Retrospectively, I was probably able to talk to more professionals over Zoom, an online video communication platform, just because it may have been easier for their schedules. Participant observation of Panel Meetings would then inform the cohesive decision-making process in action and any group discussion of ethics. In person, this occurred with many environmental constants and an unspoken professional etiquette. Over videoconference, contextual data would be relatively inconsistent, but offered insight into different facets of people during an unprecedented and vulnerable time. Finally, IRB Analysts with experience in observing meetings were asked to participate in a discussion-like group interview to save time and provide supportable data on the comparative aspects of their jobs. To increase recruitment and ease any pressure amongst BUMC IRB colleagues, this group interview developed into a Boston-area focus group of analysts and directors. Upon speaking with the analyst assigned to my proposal (and excluded from my research), they suggested that

their peers would feel more comfortable if the sample was larger. Thankfully, this focus group could also take place via Zoom. A lot of research was interrupted or restructured because of COVID-19. I was one of the luckier ones inside of my program cohort. The entire IRB felt this influx of study changes, and upon the reincorporation of in-person research again, a Panel Member remarked, "*Zoom is easier*" (2 June 2020, Panel Green).

**Research Activities**

On May 25th, 2020, George Floyd was murdered by Minneapolis police officer Derek Chauvin and the video capturing his violent death would be played on national televisions and preserved in our collective conscience. The anger and chaos that ensued, fueled further by grief of the raging pandemic and economic strife, incited a civil movement calling for the realization of racial disparity in policing and structural institutions that affect Black lives. As tensions escalated, the summer was filled with rioting and more unnecessary death at the hands of police and governmental officials. In a manner that recalls the anthropologist Jarret Zigon's notion of "moral breakdown" (Zigon 2007), the public and moral crisis provoked by the COVID-19 pandemic and George Floyd's tragic death, much like those presented on a global scale during the Nuremberg trials, draw our attention to ethical issues that, while present, may have previously been neglected in a public or institutional sphere.

Biomedicine is amongst the institutions now tasked with structural change. In addition to the real threats that underrepresented groups undergo by receiving biased care in medicine, there is multigenerational trauma that exists in communities that have a

history of being exploited by research. In serving the Boston population and specifically communities that regularly access a safety-net hospital like BMC, the IRB is tasked to reflect an in-depth understanding, if not a clear composition of its possible research subjects. During my research, the panels that I observed were somewhat diverse, but predominately white. Though this ratio may reflect the faculty at BMC, I do not believe it would accurately reflect the ratio of people who volunteer for research. In addition, and in further argument that the representation matters, when racial discussions have been brought up, it was by those few POC represented on the boards.

While observing Panel Meetings, I was able to get a feel for inner group dynamics and better understand how research decisions were made. During these meetings, it was also interesting to see the way in which the operation of institutional social hierarchies and power differentials also figured in the proceedings of the group. In comparison to in-person meetings, Zoom gave me an interesting perspective on the perils of working from home during a stressful time (children and pets made regular occurrences to meetings). On the other hand, this made me fully visible on Zoom as I obviously took notes instead of sitting in the back of the conference room. I still gathered such in-depth, handwritten notes of relevant phenomena and drew a diagram of the participants who commented at every meeting. Since being approved for research during the first week of June, I was able to observe 12 different Panel Meetings via Zoom (Blue, Green, and Orange). They each ranged from an hour to two hours long, each providing about three pages of corresponding descriptive notes. I then annotated each collection of notes into a "Fieldnotes Proper" in EverNote, a simple notetaking software. After the completion of

this research, names or initials of participants in fieldnotes and based on IRB roster were destroyed. Pseudonyms in Fieldnotes Proper and interviews will continue to remain anonymous and confidential.

In addition to attending Panel Meetings, I was able to individually interview seven Panel Members from all boards and representing all roles. This included medical doctors, scientists, and non-scientist/community members. These interviews happened sporadically throughout the summer, usually a few after every recruitment reminder that I sent out. I used a semi-structured interview guide to allow for a fluid, flexible conversation with consistent enough topics. Each of these interviews lasted 30 minutes to an hour. The focus group was also based on a semi-structured interview guide intended for analysts. Broader questions were asked to elicit discussion. Coincidentally, I ended up with three participants in relatively similar leadership roles at different Boston institutions. Because of this specific recruitment, it became an interesting conversation about the future purpose of IRBs in the research process. In recruiting for the focus group, I received only two interested analysts from within the institution, so I decided to interview them individually (which I noted as an opt-in). These two subjects were interviewed using the same guide as the focus group and each meeting lasted about an hour each. In total, I transcribed ten hours of interviews. I then used thematic analysis to code the data using NVivo. While some codes were apparent before the interviews, others were only revealed after processing and consideration of certain structural limitations. Throughout the time I spent with the IRB, it became clear that that both researchers and consenting subjects are driven by a *hope* in biomedical progress that

often manifests as an obligation or duty in the dynamic relationship of experimental science. Though each individual would engage in narrative and moral thinking in order to weigh their personal values, relative experiences, or conflicting moral registers; the overarching belief in the potential of the medical imaginary was also a clear decision-making factor on both sides of the research perspective. In addition, and in arguing for the following framework of an ethical pluralism, individuals incorporate meaning and moral value to any ethical framework they are enculturated into. The challenge begins with simultaneously identifying and universalizing the myriad of experiences and cultural values in order to meet institutional standards. I propose the following concept to do both.

# CHAPTER FOUR: ETHICAL PLURALISM

The problem begins with the notion that human lives are comparative in value, or that some are worth more than others, an ideology and worldview that is an inherently anthropological construct. In acknowledging this fact, anthropology must reorient itself or provide progressive solutions to this categorical axiology.

## Anthropology's Worldview

According to the American Anthropological Association website, anthropology is defined as "the study of what makes us human" (American Anthropological Association, 2021). In addition, Merriam-Webster lists two definitions of anthropology, 1) "the science of humanity; especially: the study of human beings and their ancestors through time and space and in relation to physical character, environmental and social relations, and culture" and 2) "theology dealing with the origin, nature, and destiny of human beings" (Merriam-Webster 2021).

With such all-encompassing aspects, anthropology is revered as a holistic science that attempts to understand, or at least to classify the myriad of human experience. Though it touts a scientific objectivity, this categorical axiology, which names and values things as an increasingly pluralistic and inherently subjective viewpoint of the world, depends wholly on an anthropologist's positionality. Thus, in a philosophical understanding of anthropology, the discipline unintentionally attributes value to everything it names. This axiology, or "study of value" is synchronous to any systemic study of human behavior and agency. There is no other way of understanding things

relationally without attributing a value to them. What ethical anthropologists (and all scientists and theorists) must do then, is understand this inherent subjectivity and identify how their own relative values influence their positionality.

**Navigating Ethical Worlds**

By understanding morality as an amalgam of evaluative experiences and discursive styles that exist in parallel, the concept of moral registers is useful in theorizing how actors in modern societies may inhabit and negotiate meaning between different situations and ethical worlds. Though individuals may subscribe to overarching ethical views, it is important to conceptualize the complexity of contradicting subjectivities within certain circumstances.

While culturally dependent, each moral "register" is marked by different degrees of formalization and institutional control. Some have more authority than others, and some call for complex negotiations between dynamic understandings. While there are countless different articulations of these registers, as demonstrated in Schielke's ethnographic population and argument, there may not be a clear or agreed consensus on what exactly constitutes a moral register for different people, and precisely where it should apply. For example, members of IRB Panels must think in registers between personal and professional ethics and experiences. Though they inhabit a joint bioethical register, many of the individuals I spoke with understood and attributed their personal ethics to various other sources.

When asked if they thought of themselves as "ethical people", many individuals often framed an answer around what type of upbringing they had. One participant started, "Um, I think a lot of it comes from my parents, uh... and also from my religious faith," continuing, "My mom was--grew up in the Quaker tradition, which was, uh, really *really* focused on that, and she communicated a lot of that to us," (G1). Elucidated as somewhat intrinsic *tools*, this participant articulated these notions as something that just came easy to them. Later, when asked if these same ethics were ever challenged within the IRB setting, they thoughtfully stated:

> "Well, let's see... Probably. Probably. Yes. Well, actually, yeah. There are a few things. I think, um...One of the things that I think sometimes," they laugh to themselves, "when we go over these studies is that, if I can possibly avoid it, I would never do any of these on myself. I would never be a subject. Because I feel that the human subjects in most clinical trials are—are *rental bodies*, right? You have somebody in a trial sponsored by a huge, multi-quadruple billion-dollar company for four or five years and somebody's going to be reimbursed like $15 a visit, or $50 a visit, and this drug company will then take the information that they get--by *renting* people's bodies, essentially, and they're going to make insane amounts of money. Um—I find that *abhorrent*" (G1).

So, how can someone who would never join a biomedical study themselves be fit to negotiate bioethics? By occupying other moral registers of relevant ethical experiences, this community member was actually one of the most experienced and engaging participants I spoke with. When we later discussed what happens when questionable

studies come to the board, they first note their experiential knowledge within a biomedical context by stating, "*This is an example of me swinging at the ball and hoping it goes over the fence*," and continue with an example from a recent meeting we had both attended where they had spoken up:

> "I don't know if it was totally appropriate or applicable, but I did share my patient perspective about adverse events. I was seeing my neurologist recently and I was telling him about some side effects from a medication that I routinely get, and he was a little bit like, 'Talk to the hand,' you know?" They start again, "I mean, it was like, 'this medication is has been around forever, and it's 98% perfect' and it's like—a lot of times people don't want to hear this. And the idea that, you know, there'd be nobody to even really take the complaint seriously, whatever it might be, whatever the adverse event might be, to me, was just wrong. And so, you know, I-I, you know, make my opinion known. And I'm sure that it's taken within a certain frame of reference, but I felt *good* about helping to move that along, as much as I could," (G1).

Using both their ethical groundings and their experiences as a patient, this Panel Member traversed between different moral registers in order to empathize and reason with bioethical decision-making. They also make note of their role as a non-scientist member and how their experiential knowledge may be weighed differently by the board because of it. In a similar conception, another Member I spoke with also attributed their moral foundation to their religious upbringing:

> "Well, I think--I think that... That my parents, certainly provided plenty of that. I guess it starts with that, and, you know... I feel that it's important to try to do the right thing. I have an interesting background in regard to that, I am mennonite, I'm actually not a practicing mennonite, but my parents--and my dad was a theology professor." (O2).

They go on to denote a valued sense of fairness through experience and having a good education, but have trouble describing exactly *where* else their ethics may come from. Later, in describing what makes them an effective IRB member, they state, "I try very hard to see protocols that we review as both from the subjects' point of view and from the investigators point of view" (O2). As both a researcher and medical doctor, this member also occupies various moral registers that they must consider while making study determinations.

While still largely referencing childhood, another Panel Member thinks a moment, but in contrast, states, "Um," they sigh, "that is a hard one. Um… I didn't grow up religious. So that's a, sort of a clear…" they pause, "*place* to get morality for a lot of people, I think, (G2). Interestingly, while simultaneously disclosing a lack of religious foundation, this member still recognizes its ethical relevance and overlap with bioethical judgement. They go on to say, "I think that my family was always committed to uh, to social justice and people with less means," they explain, also remarking on the effects of traveling to different cultures and meeting people with diverse backgrounds. Following this view, the enculturation of different moral registers seems to inform a further evaluative and pluralizing sense of ethics.

Another member also noted ethical relevance in defining cultural experiences, stating, “I grew up... you know, 60 miles from the Mexican border. So, I obviously saw a divergence on how people were treated when it came to healthcare, and how they got access to healthcare” (O3). They continue “It's—it’s just a... a boiling pot of rage and racism out there, and it's terrible and horrible. And so, it's *those* things, growing up and seeing that, and seeing the lack of connection that has driven me to want to be involved in making sure that everything's done appropriately,” (O3).

Also relegating an abstract obligation to fairness, this demonstrated subjectivity is experiential and highly empathetic. Moral registers may exist in many incomprehensible forms, but as demonstrated in these examples, a consistent theme throughout this research and within each characterizable register has been on the moral development of the *self* and an empathetic consideration of the *other*. There is clearly a sense of right and wrong that comes only from evaluating our own experiences together with a group. In further developing Samuli Schielke’s concept of moral registers and ethical pluralism, the foundational orientation of self and personality structure developed within an individual’s cultural environment is highly dependent on their conscious level of socialization. In other words, once a person is conscious of their moral register, they can start to recognize and potentially engage simultaneous ones.

**Forces of Ethical Decision-Making**

*“Narrative thinking” (Cheryl Mattingly 1998) and Moral Thinking*

In order to consider the large diversity of methodology and application of biomedical research from multiple perspectives, IRBs consist of a group of individuals with various roles, specialties, and ideologies. These ethics committees are an attempt at objective consensus on research parameters through negotiation. Beyond their professional expertise, each individual on the board engages in narrative and moral thinking that is specific to their cultural worldview, conflicting or incommensurable registers, and personal experiences. By using these forms of experiential thinking, individuals often recall past memories and construct narratives in a story-like way to understand themselves and engage with their current reality. By considering past experiences in tandem with one's current reality or problem, narrative thinking becomes moral when it is capable of imagining the possibilities of the future and thus one's obligations through time. This "plot-like" understanding of reality is where humans retrospectively construct meaning and similarly heightens our sense of obligation and *place* in time.

Anthropologist Cheryl Mattingly describes narrative thinking as "our primary way of making sense of human experience" that we do "primarily through an investigation of human motives" (Mattingly 1991, 999). Contrary to our traditional biomedical investigation, narrative thinking does not attempt objectivity. Encapsulating moral thinking—or rather, the broader form of moral thinking—narrative thinking is the capacity to organize and remember your experiences as subjective knowledge rendered in a story-like format and used to understand the present.

This phenomenological approach to narrative thinking focuses not only on how a person experiences and makes sense of a problem, but also how their experiences define their understanding of and retroactively construct meaning from that phenomena. Moral thinking is thus a specific form of narrative thinking that adds cultural frameworks of ethics and purpose to an individual's understanding.

Within someone's individual experiences and conflicting moral registers, concepts like risk and benefit are highly subjective. In the context of the IRB, particular worldviews and experiences can change what someone considers dangerous or worth the potential harm of research. Therefore, because such ambiguous concepts can be understood so vastly differently, IRBs have specifically defined these concepts as bioethical principles for their board members to understand and aid in determining the potential harm of experimental research. Nonetheless, each individual's experiences and accumulated knowledge change what they may interpret as ethical.

*"Objective self-fashioning" (Joseph Dumit 1997) and The Future*

Joseph Dumit introduces the concept of "objective self-fashioning" in "A Digital Image of the Category of the Person," to explain "how we take facts about ourselves—about our bodies, minds capacities, traits, states, limitations, propensities, etc.—that we have read, heard, or otherwise encountered in the world, and incorporate them into our lives" (Dumit 1997, 367). In ethical terms, Dumit explains that it is the acknowledgement and incorporations of "local mutations" in persons as they happen. Borrowing from anthropological theories of phenomenology, Dumit uses the objective self to represent the

practical embodiment of meaningful knowledge. He states that, "From one perspective, science produces facts that define who our selves are objectively, which we then accept;" He continues, "From another perspective, our selves are fashioned by us out of the facts available to us from through the media, and these categories of persons are in turn the cultural basis from which new theories of human nature are constructed (Dumit 1997, 367). He is a suggesting a continuous synthesis of self that arises from what we know and learn about the world.

For example, Dumit illustrates his case in how PET scans are used as "authoritative facts" about how "the world and bodies objectively are" (Dumit 1997, 368). In the IRB, this can be observed in the declaration and subsequent upholding of the abstract principles of human subjects research first published in the Belmont Report as "beneficence, justice, and respect for persons" (Belmont Report 1979; HHS Website). More specifically, in the pursuit of scientific discovery or exploratory medicine, or any other weighing of unknown risk and benefit, presupposed "objective facts" about the world are taken *a priori* into decision-making.

In other words, we internalize moral facts about the world and incorporate them into our engagements and relationships – we *prescribe* meaning that then defines our cultural understandings of such processes. The more knowledge and experience one has about some subject or phenomena, the more likely they are to fundamentally believe it to be true. This concept is similar to that of Bourdieu's *habitus* in that it considers how the taken-for-granted and everyday "being-in-the-world" affects an individual's decision-making (Bourdieu 1986; Heidegger 1927; quoted in Zigon 2007). In free-thinking

individuals, these moral foundations can shape the ability to empathize, and within the IRB, apply reasoning of risk and benefit beyond the physical self.

### *"Mission Creep" (C.K. Gunsalas et al. 2006, 2007; Rena Lederman 2006) and A Priori Decisions*

The idea of "mission creep" was first conceptualized by C.K. Gunsalas et al. in 2006 after wanting to understand how IRBs were operating under increasing responsibilities and without adequate resources for thorough ethical consideration of all studies. Panel members and IRB analysts usually practice an abundance of caution in order to protect study participants, but following specific protocol in order to meet institutional mandates and guidance, on top of an already strained administrative system, creates grey areas of research protections when considering a myriad of contextual factors. "Mission creep" was introduced by C.K. Gunsalus et al. in 2006 and is still applied in social science research in various contexts. It is defined as the state when "the workload of IRBs has expanded beyond their ability to handle effectively" and further:

> "Mission creep is caused by rewarding wrong behaviors, such as focusing more on procedures and documentation than difficult ethical questions; unclear definitions, which lead to unclear responsibilities; efforts to comply with unwieldy federal requirements even when research is not federally funded; exaggerated precautions to protect against program shutdowns; and efforts to protect against lawsuits" (Gunsalus et al. 2007, 617).

Within a biomedical model, this can specifically be understood as routinely following highly idealized policy as a standardized practice without sufficient consideration to contextual factors. Contrary to the growth of practices oriented toward medical and "ethical pluralism", "structural factors still incline the federal system, through local IRBs, toward applying one homogeneous ethical standard, based on one concept of "best practice" […] abstracted from clinical biomedicine and experimental behavioral research" (Lederman 2006, 486). Thus, the problem with mission creep is not the standardization of ethics, or the a priori assumption of ethical relativism, but the inclination that the relevant ethics are not even considered in the process. In tandem, mission creep also refers to the problems of applying these same ambiguous ethical practices and frameworks to very different fields and data. Instead of drawing from personal experience and diverse moral registers, individuals are expected to reason within a tightly scripted and controlled set of bioethical parameters in a reflection of the highly legalized environment.

In a Focus Group of Boston-area IRB Directors, I ask how the analysts and directors' roles within the institution were different from the Panel Members tasked with study reviews and ultimate decision-making. One individual articulates the difficulties of meeting regulations:

> "I would say we try not to *lead* them in the decision, because I think... you know, It—it doesn't respect the process, but at the same time, you know, there are some protocols where, you know, you say to yourself, 'if I give it to that person, they're going to make a big deal about the stuff that is not really a big deal, and if I give

to that person they're going to miss these things that I think are important, because they never look at that,' you know, so you get to know your members after a while, so there's a lot of like, probably *unintentional* leading that happens, and sometimes it's less, it's a little less…I think it's--it's rare, though, it's usually--you know, usually a lot of the work is done for anything that goes to our committee members" (D1).

As this Director indicates, members often get to know each other quite well during their time on the board. This includes kinds of expertise or any specific problems that each individual may raise. They continue:

> "We do a lot of work, tidying things up--getting clarifications, getting the researchers to complete their answers so that the board members have the information that they *need* to determine if it meets the criteria for approval, and things like that. In that process, I think that--that the committee members being able to read our back and forth and the questions that we raise and the way we raise them with the study team, that I'm sure *flavors* their review, you know, because they're looking at the questions, the hard questions that we ask, and maybe the *critiques*, and so, you know, the bias is there, regardless, you know…" They trail off and then finish, "So, we're all part of the same—the human research protection program...it's everyone's job to *tidy it up*" (D1).

From the time that a study proposal leaves a researcher, it has been "tidied up" at least once by the IRB analysts who serve as a first line of communication between the board and institution. Often formulating it using a specific template and language, a study will

not progress to the board for a vote, much less be deemed "ethical for research," if it does not follow strict institutional regulations.

Lederman argues, "Whether followed to the letter or more loosely, the guidebook's interpretation of the regulations is troubling not because it recognizes that methods and ethics are inextricable but because it encourages IRBs to adopt a single, narrow model of adequate research design" (Lederman 2006, 486-487). When mission creep occurs, IRB and other policy-driven entities "objectively self-fashion," or *prescribe* a homogeneous ethical standard to meet the criteria of biomedical research ethics.

A good panel member is someone "who's engaged in the process, but also understands their role" (D1). When this role is standardized to perpetuate prescribed ethics, mission creep can occur because it is simply easier to follow the rules. IRB directors and analysts provide the federal and institutional guidance to panel members on the definition of ethical research. Within these parameters, the mission of the IRB is to protect human subjects, but can this be interpreted differently? The institutional process is supposed to help. "So, someone who knows what they're supposed to look at and why doesn't *dig*—doesn't spend a lot of time digging up things that don't need to be discussed or prodded or poked" (D1).

To clarify, this needs to be understood under the mounting time constraints and institutional responsibilities that Gunsalus et al. (2006) understood and noted in their definition of mission creep. IRBs are expected to orchestrate and fulfill a number of roles within the growing biomedical research machine. Considering this context, another director agreed,

> "There will be people who can sort of nitpick every little thing or get really deep into the weeds on methods when we have to kind of push them back and be like, okay, but like, let's try to look at it more from like an ethical and actual protection of human subjects, rather than getting really hung up on the, you know, the sampling frame and the methodology that they're using because that does happen sometimes" (D3).

In an already strained system, the roles that inform and then construct the ethical perspectives of research are integral to the interpretation of what is scientifically objective. Thus, mission creep can occur both because it is easier and because it encouraged. "When people do that. It hurts. It hurts the whole program. If you don't pick your battles." (D1).

In short, policy enacted by IRBs and other decision-making entities of demonstrative and moral authority define and perpetuate their own culture of ethics. By incorporating a regime of *ethical pluralism* – the idea that differing moral values are dependent on an individual's understanding of the world – institutions or any form of representative power can make more informed decisions for their constituents.

## Advancing Current Institutional Practice

### *Medical and "Ethical Pluralism"*

Medical pluralism, or the concept that within a given setting, a variety of healing modalities are theoretically accessible, is "to get a handle on these different dimensions of social complexity in particular local settings, and their meanings for those involved"

(Barnes 2007, 47). Barnes continues, "It is to track the fluid dynamics internal to different medical systems, the interplay and contests between them, and the resulting hybrid forms that emerge" (Barnes 2007, 47). Because this idea came out of realizing the inherent power differential between ethnomedical systems and the growth of Western biomedicine, it is also an intrinsically *comparative* concept. When considering plural systems and efficacy, this axiological perspective is necessary for any comprehensive and objective truth of health.

Borrowing from this concept, institutional policies generally amalgamize applied moral values while the embodied life experiences of different groups or individuals may reflect distinct ideologies or moral priorities. In biomedical research contexts, each individual, distinct committees, and Institutional Review Boards may interpret the praxis of human subjects protection in different ways. By imposing this objective standard of overarching ethics, institutional policy may reject the coexistence of plural ethical worldviews.

For example, while having community members with specialty knowledge usually integrates the layperson's understanding of a research proposal, they may not always represent the culture of ethics within the research population. Though they must often attempt to embody the perspective of the subject in research, it usually takes some narrative reasoning with personal knowledge or ethics to fully encompass the complexity of the moral problem.

During my internship with the IRB in early February, this problem is demonstrated when the issue of a subject being in an abusive relationship is brought up.

As one member later remarked, “The IRB is great about thinking about *privacy*...but they don't often jump to the connection of safety” (B2). This specific study garnered enough caution by the IRB to bring in multiple outside educational resources on background study information and community context. While this study demonstrates the large capacity of outside expertise available to the institution, it was also specifically concentrated on protecting the subject *from* risk of violent retaliation.

When later asked what would happen if this kind of knowledge were unknowable about the research population, this member continued:

> “So, it's one thing if a family member learns, you know, you're in a study that they didn't know about, or maybe even learns, you have a condition that they didn't know about you, and you might be embarrassed, you might be—*whatever*, lots of things that you might be… But if there's also going to be some kind of consequence—like if you have an abusive family member or an abusive partner that's going to actually *retaliate* against you because you were involved in something, or telling people, ‘our business’ or you know… the types of things the IRB already is set up to do really well are really important to do because some people are in situations where it could actually be dangerous for these types of privacy to be violated” (B2).

In other words, it takes someone to be able to recognize and empathize with what *could be* at stake. I include another narrative example below.

> *When I begin my fieldwork in June, the panel looks a little different. I jokingly start titling my fieldnotes, “Quarantine Series” (while an end was still in*

*sight) to make sense and light of the rows of Zoom squares on my computer screen. When I am let into the Blue Panel meeting on June 18th, 2020, I hear someone say, "I don't have COVID, but I can't keep track of time," (June 18th, 2020; Panel Blue) and with dark circles under my eyes, I nod in quiet agreement.*

*I give my announcement for research on this day, and I note in my journal that my voice is a bit shaky. I do not recruit anyone, but the newest analyst—who is ineligible by my design—sends me a reassuring chat message that they thought it went well. I stare at the little smiley emoji and am genuinely surprised by how thoughtful everyone is to a young researcher interrupting and observing their meeting. In what I can assume is common among the other non-scientists on the board, I have trouble keeping up with a lot of the more biomedical studies, and I unintentionally become more interested if it pertains to a topic of research I recognize. For example, an international study presented during this meeting focused on a population of pregnant women who would be asked to give consent of research upon arriving to a community hospital to give birth. As an anthropologist and a woman, I was keen to understand the dimensions of ethics and narrative reasoning used for board members who were neither. Almost immediately, a community member questions the ability to give informed consent under pregnancy stress and is met with discussion from two other members who define their own labor experiences of acute stress. A visiting physician taking part in the IRB Internship Program even offers their knowledge of the population and a concern about culturally influenced power dynamics.*

As illustrated, a group of individuals may all similarly understand a problem when placed within the same strictly biomedical framework, but when questions of ethics arise that demand reasoning with one's own moral foundations and life experiences, the answer becomes much more complex than right and wrong; the consideration of a plurality of moral registers is necessary to solve problems that are felt outside of biomedicine. *Ethical pluralism* is a concept that attempts to bridge this gap between individual life experiences and cultural humility.

"Ethical pluralism" differs from traditional "value pluralism" in philosophy by incorporating the anthropological concept of cultural relativism (Mason 2018). While it accepts value pluralism as a normative claim that there *are* many different moral values that cannot be essentialized, ethical pluralism entails that *all* values or value systems should be considered equally *true*. In other words, a value pluralist believes that "the good life" entails different values of friendship, happiness, liberty, and so on that cannot be reduced to a single unit of "goodness"—these values are not the same. An ethical pluralist accepts this claim and understands the relativistic implications on cultural worldviews—some of these values are more significant to some cultures than others. Additionally, "moral [or ethical] relativism is the view that moral judgments, beliefs about right and wrong, good and bad, not only vary greatly across time and contexts, but that their correctness is dependent on or relative to individual or cultural perspectives and frameworks" (Baghramian 2019). A variation or specific cultural relativism, ethical relativism is the claim that all value judgements are dependent on cultural norms. Ethical pluralism also encapsulates this idea, but argues for the justification of overarching

universalities toward “the good life” or “relative goodness” for all. Because of the incommensurability of moral registers within each complex individuals’ life, notions of right and wrong may be to some degree relative or inconsistent, but a respect for all values is not. Further, ethical pluralism accepts that ethics change over time. It not only allows for this change, but encourages the growth of perspectives in order to progress and evaluate collectively.

Institutional Review Boards demonstrate some basic structural frameworks of ethical pluralism by facilitating the discussion of Panel Members representing diverse roles and inhabiting differing moral registers. By encouraging the sharing of narrative reasoning and experiential knowledge, the IRB provides an environment and culture for the creation of its own comprehensive and evolving moral register. In practice, however, these deliberations are still susceptible to institutional politics, power dynamics, and a representative’s positionality.

Considering the history that led to the necessity of an ethics committee in biomedical research, ambiguous policy is “problematic if it reproduces colonial relationships, ignores community input into agenda and risk, offers no real possibility for improving human life, or uses so loose a methodology that it cannot be relied upon to produce scientifically valid data” (Hodge 2013, 287). When “mission creep” occurs, IRB and other policy-driven entities “objectively self-fashion” a homogeneous ethical standard to meet the criteria of their own ethics (Dumit 1997).

Therefore, and following Dumit’s theory of the “objective self,” biomedical ethics committees must engage in medical and ethical pluralism to uphold a standard of

conceptual-objectivity and adaptive progress. Further, ethical pluralism is necessary in any place of relative power where institutions are required to make decisions on an individual's behalf. Considering the power of enculturation by our decision-making entities, further anthropological research is needed to identify and define the conceptual moral groundings of representatively "ethical" people.

# CHAPTER FIVE: THE ENCULTURATION OF EMPATHY

Empathy and empathetic decision-making can be enculturated as a form of moral or narrative thinking in populations tasked with representative authority. In ethical dilemmas, multiple perspectives are needed to be considered in the pragmatic determination of best solutions for multiple peoples. By participating in the ethical and empathetic consideration of differing moral values, consideration is encouraged and enculturated into the group. Through processes of self-reflection and the dynamic weighing of different subjective experiences, individuals can enculturate an ethical pluralism to investigate and empathetically influence further moral and narrative reasoning.

## Empathetic Decision-Making

As stated in the Background Section of this thesis, the Belmont Report was drafted in response to public realization and outcry over unethical research conducted in Tuskegee and during WWII. This established the early concept of an Institutional Review Board and laid its framework with the mandated principles of "respect for persons," "beneficence," and "justice" when conducting biomedical research.

Ethical research involving human subjects must therefore understand and reflect this commandment of individual integrity inherent in the Belmont principles in order to be considered and approved. In institutions such as the IRB, empathy is employed as a form of moral and narrative thinking to investigate the ethical dimensions of biomedical research. Group decision-making takes the consideration of multiple perspectives and

experiences in order to articulate the best solution to a complex problem without a 'right' answer.

In the protection of human subjects, a moral value is attributed to the broad capacity for individual human experience. A human subject is defined to a body that varies by circumstance and experience and experiences life through that anonymous body. Though the value attributed to a research subject may be abstract, it is still a moral one. In attributing moral value to the subject, the researcher and institutional structures that claim to protect them must consider their life to have value in itself. Those tasked with understanding the perspective of another use moral thinking guided by empathy to recognize their humanity in an anonymous *other*.

Panel Members must occupy various roles when considering the purpose and potential repercussions of biomedical research. While primarily divided into MDs and scientists adjacent to non-scientists and community members, all roles must apply their subjective knowledge to understand the researcher *and* subject perspective. Using moral thinking about personal experiences and narratives, board members must weigh their own ethics against those of the institution in a pragmatic consideration of the potential for scientific progress. Sometimes, there is a clear difference in perspective and relative understanding between represented members on the board, as this community member aptly noted:

> "Nobody--nobody's trying to have blinders on, but if you have a room full of medical professionals, people are just going to operate in that *mode*, and with a certain shorthand, and to move things along, and to have to have a "regular

person" *(finger quotes*) in the room, is *very* important; and going over the consent forms is a big part of what I do, and I remember during one of the first meetings I was at, I had gone over a consent form and I was reviewing what I found and there was one phrase in Latin, and it was part of a sentence that said, 'Patients should also be warned about... *this Latin phrase*,' and I said, *Oh!* I said, 'what does that mean?' And they said, 'oh, that means *death!*' And I said, 'Well... you know *(smiling)*, it might be a really good idea to put that *in English* because most people can't read Latin,'--and it was just, it was just, I guess, a term that was typically used in medicine, um, that *probably* very few normal, everyday patients, would *know* and they might just zip right past it and sign off on the bottom. And I said, *(laughs)* 'You've really gotta--gotta let people *know* this stuff because that's--*that's important* (stops laughing, tightens face and looks concerned), and *I* would want to know that, and the whole table erupted in laughter--but it's not... it's not *funny*, you know, I mean, it was, in the moment, but it's... It's *important*" (G1).

As demonstrated, subjective and individual understandings of complex concepts can highly influence group-decision making. This member was capable of considering the subject perspective because of their own experiences, or lack thereof, in healthcare. The moral value attributed to the subject comes from the empathetic capability to recognize and relate to them. Later, this member would tell me that though they did not feel they were representative of the BMC patient population, they felt that their own health issues and success with experimental medicine aided their considerations for the review of research.

**The Anthropological Perspective of Empathy**

The motivation behind empathetic and seemingly altruistic decision-making has alluded human thinkers for centuries. Though empathy is specifically defined by each discipline that attempts to understand it, all "usually emphasize that it is a way of recognizing and assessing what another person is thinking, feeling, doing, or intending from a quasi-first-person perspective, and that this process involves both cognitive and emotional aspects" (Hollan 2014, 3). It is a seemingly intuitive way of understanding human behavior. Using the anthropological perspective, empathy also "reflects survival strategies that have been highly refined by the physical and social parameters of our environment," and is further refined by the experimental and experiential cultural response process over time (Hurlbut 2002, 5).

In the process of understanding the self, one becomes aware of the separate existence and experiences of the *other*. Whether one values this other existence *in itself* or in recognition of a likeliness to their own experience is dependent on their capability of empathetic consideration and moral thought. Anthropologist Douglas Hollan notes that "for many researchers, this is what distinguishes empathy from 'sympathy,' 'compassion,' 'pity,' or some form of emotional contagion," by including the distinction of imaginative thought of another's experience. He further elaborates:

> "Formal definitions also usually note that while empathy entails an emotional resonance between the empathizer and the object of empathy, it is also characterized by the maintenance of a clear cognitive and experiential boundary

between the two, such that the empathizer can always distinguish between her own thoughts and feelings and those of the other" (Hollan 2014, 2-3).

While sympathy denotes a shared feeling, empathy includes the understanding and conceptualization of the other as *distinct* but ontologically parallel to the self. Further, sympathy conveys an understanding and assertion of a shared emotion—*I see and share your feelings*, while empathy is the recognition of a separate experience that is familiar—*I understand how and why you feel*. Valuing others as experiential beings takes a recognition of your own self-consciousness and seeing that capability in another.

According to developmental theories put forth in the "Kohlberg Stages of Moral Development" (Kohlberg and Hersh 1977) and originally defined by Jean Piaget (1932), children begin to understand a sense of self and other and engage in social interaction within the "Conventional Level" of moral development. They state that, "moral judgement, while primarily a rational operation, is influenced by affective factors such as the ability to empathize and the capacity for guilt," As an individual becomes more socialized within their environment, their point-of-view must change in order to participate in groups. "But moral situations are defined cognitively by the judging individual *in* social interactions," (*my emphasis*). They conclude, "It is this interaction with one's environment which determines development of moral reasoning," (Kohlberg and Hersh 1977, 57). In other words, an individual's moral development depends on their socialization and "reworking of one's role-taking experiences" in an increasingly complex web of relationships.

Before long, such reasoning processes begin to take shape and action closely follows a recognition of agency. As the Stanford neurobiologist William Hurlbut states: "Moral thinking is inherent in the development of human consciousness, for as the self becomes aware of other selves, the ethical issue inescapably arises as to how one person should treat another. The mind is irreducibly transactional, defined in a "conversation" that is grounded in empathy and experienced in community" (Hurlbut 2002, 12). As one experiences the more complex *other*, they theoretically begin to understand the myriad of human reasoning and experience. Kohlberg and Hersh state, "this interactionist definition of moral development demands an environment which will facilitate dialogue between the self and others," meaning an environment in which ethical discussions can take place. Following these theories of development, "The more one encounters situations of moral conflict that are not adequately resolved by one's present reasoning structure, the more likely one is to develop more complex ways of thinking about and resolving such conflict," (Kohlberg and Hersh 1977, 57).

As demonstrated in recent studies by prominent evolutionary anthropologist, Michael Tomasello, the biological drive for humans to cooperate can be traced back to our primate ancestors (Tomasello, 2014). It has what has led to the development of cultures through time. Beyond this, there is clearly an abstract capacity for empathetic reasoning that is instilled in normal human development. Therefore, empathy should exist across a spectrum, but there is still little to no anthropological research confounding or exploring this claim. Further, these theories denote that if someone is incapable of inclinations of moral decision-making, there would seem to be either something

biologically or psychologically inept about their personality development. Moral development usually takes place in childhood, but it is evidently also firmly based on an individual's sociality. Empathetic consideration necessitates both a conceptualization of *your* humanity and a recognition of the same, *distinct* and equally valued humanity in another. In the protection of human subjects, moral thinking surrounding the capacity for experiential potential is taught and reflected in the calculation of risk and benefit for the greater good. In these spaces of ethical discourse, there is dire need for a framework of ethical pluralism in order to continuously understand and uphold different cultural values.

**Defining 'Bioethical People'**

In providing adequate knowledge and representation to the research subject, IRBs approve research proposals only with various levels of review from a diverse range of perspectives pertaining to biomedical intervention. As a first line of communication for investigators, IRB Analysts provide methodological and clinical insight on a broad scope of research within the institution. For more complex studies, Panel Members are individuals selected for their expertise and subjective knowledge of disciplines to provide a specific viewpoint or medical perspective in both deciding and representing the ethical dimensions of a scientific study. They are usually also representative of some department, specialty, or community. The Panels themselves are separated into different boards that meet on a biweekly basis. At BMC, I was able to observe three out of five of these panels. From what I could gather from multiple interviews, the different boards were originally created to handle specific types of research (one panel for drug trials, one panel

for behavioral research, etc.), but now handle studies interchangeably. This makeup varies by institution and depends on reaching a "quorum" or 6 Panel Members in attendance. A Panel Chair that I spoke with expressed the IRB's challenge to recruit Panel Members, "I think, first of all, the IRB administration, they--they're happy to get people who want to be on the IRB. It's a volunteer position," (O2). Though the recruitment process also varies by institution, the members I spoke with were mostly recruited through some informational or specific communication with IRB Directors or administration. Some specific narratives of recruitment are listed below:

> "I went to an education seminar, so they're giving some education on, you know, one of their monthly seminars, teaching you about something--I don't remember what it was, but they made a mention that they were always happy to entertain new board members. So, I approached them after that" (O3).

> "In my working career, I was an administrator of several of the GCRCs--General Clinical Research Centers at area hospitals... Brigham Beth Israel and [Boston] Children's and a good friend of mine was the administrator at BU, and they were looking for--she was a member of the IRB there, and they were looking for new members, non-institutional members, and she recommended me" (O1).

> "I had a very close mentorship relationship the original Research Director in (a) Department of Boston City Hospital—actually, was the one of the people who

> actually *engaged* me, invited me to become part of the Boston City Hospital IRB for those reasons, she said both: it helps to bring the perspective of the specialty to some of the research proposals that we are reviewing […], but also that you will really benefit, ” (B1).

Because it is a volunteer and unpaid position, I found that membership is generally sought out by someone interested in the research mechanism or persuaded directly by someone within the institution. Though both of these situations demonstrate some intuitive sense of ethics, either from the inclination of the person themselves or from the IRB's perspective, it also clearly shows a disconnection in the meaning of ethical representation.

Beyond the institutional need for more expansive forms of recruitment, I found the current composition of the IRB interesting when it came to internal power dynamics and presenting different forms of knowledge. During Panel Meetings, expert knowledge is usually exemplified and prioritized by assigning a lead reviewer to relevant studies. While other members are also expected to review all studies, they serve as secondary and often less authoritative reviewers of the research or ethical problem at hand. Within a biomedical institution, this expertise is often delegated to the medical and scientific members of the board, while community and non-scientist members are often designated as a follow-up and specialty consideration when needed.

When I asked a community member if they felt this distinction made them feel listened to any less, they said,

> "Sometimes, people treat me like I'm...(*thinking)* the pet cat who walked in. You know? I mean, and—and nobody is doing it in a negative way, but there are people who will sort of say, 'Oh, you're the most important person in the room,' and it's like, no, no, I'm really not, and it's okay, and I know you're trying to make me feel special... Um, but sometimes it comes off a little funny... uh, and I just smile and everybody's very kind and I really like them and they like me. It's just, I'm not a doctor, you know, or a nurse" (G1).

Alternatively, as a representative community member, this individual was consistently able to provide their personal knowledge and life experiences in the deliberation of the panel. They identify the way medical doctors and scientists treat them on the board as "special," in a manner that some sense entails a condescending tone.

**Moral Foundations and Development**

In attempting to understand why Panel Members may be drawn to representative, ethical positions like the IRB, I wanted to ask where members felt their ethics came from. What led someone to join an ethics board? What kind of qualifications are even measured for such an evaluative position? Do representative people see their own perspective as related to how and *why* they make these difficult decisions? It may take empathy to consider other perspectives, but was it what brought them here? In asking where these moral registers seem to come from, narratives of family, religious, cultural, and patient experiences mold an understanding of human complexity, and perhaps better articulates what it takes to ask someone to be a representatively 'ethical person'.

When asked if they thought of themselves as ethical, one member stated, “I live a very entitled life, and I'm really aware of that, as compared to a lot of other people, certainly as compared to most of the patients I've met at BMC--I did some volunteer chaplaincy up there,” they added, noting both their distinction from and community involvement in religious service. They continue:

> “So, and--and I was born into that situation. I did not...earn that, um... so, I think--I think it's very easy for me to be "ethical" (*they say with finger quotes*) because my life is not hard. I think--I mean, I think, yeah, I think I'm an ethical person. I think it's easy for me to be ethical. You know, I don't want to make myself sound, (*they pause and laugh*) more *noble* than I am, or am not, right? You know, because this isn't hard for me to do. I have the time and the tools and those were given--sort of given to me, really” (G1).

It is a hard question to answer, and they understandably double back when given time to think about it. Are ethical people those who it comes easy to? In comparison, another member notes their self-identified affluence when asked about their moral foundations by stating:

> “Well, I grew up in the south and a lot of my like, women who took care of me--my mom worked full time, so the women who took care of me were often from much different backgrounds, much more lower income backgrounds, and I became close to them and their families. And you know, I think, seeing how different people who lived in, how people with less money, you know, suffered in myriad ways made a big impression on me, and then I traveled a lot when I was a

younger adult […] *I don't know*. I think…I think just seeing how other people live, and also, I think just having low wage jobs, which I had in high school and in college was helpful in caring about it…" (G2).

In this member's response, there is again a clear distinction between themselves and those they consider to be vulnerable. This perspective of the self, even in privileged circumstances, is the basis of empathy identified in the previous section on moral development. They continue, "Yeah, I guess one of my guiding principles…is concern for the most vulnerable in society" (G2). Elaborating further:

"I mean, I think, I think concern for people--vulnerable people--people with less money, or lower health literacy, or, you know, immigrants, people with mental illness. I mean, that's…um like basically people--and children (*emphasized, louder*), people who can't necessarily make a—you know, have pressures on them that would make it difficult for them to make a decision that always keeps their best interest in mind like that--that would be a guiding principle for me, in the—in my IRB work" (G2).

Another member identified a religious background and household, again solidifying this association with emphasis, "I think that I have a strong sense of doing the right thing, the importance of doing the right thing and of being fair. I think those are kind of related--but I can't cite other than I was certainly brought up that way," (O2). They take a moment before starting again,

"I don't know that I have any... You know, I've certainly seen *unfairness (articulated)* in my life over the years, and-and don't like it, and I certainly don't

like it when it's directed at me, but I also recognize it when it's directed at other people and--and I feel very strongly the importance of being fair, and treating people the same, and giving everyone an opportunity that is... That allows them to stand or fall, you know, as opposed to imposing things on them" (O2).

All of the Panel Members that I spoke with took careful time to think about how best to articulate their ethics. They were usually surprised by the question, but intrigued, and would often look off in the distance with glassy eyes in order to find the words. It's a hard thing to do, or maybe *locate*, and the answers I received all seemed to stem from the defining institutions that stick out in an individual's lifetime like religion and family. After the first incantations, there seemed to always be a bit of unease before divulging something more specific that *proved* they were a morally upstanding person. Though difficult to articulate, I found it surprising that most Panel Members, a role tasked with contributing to the meaning of bioethics, had never thought much of their own. If ethical representation cannot identify itself or its meaning, even with an intuitive sense of empathy, its purpose becomes even further misunderstood and potentially misapplied. The disassociation in purpose is not confined to the IRB but any representative institution of voluntary commitment to an ambiguous ethic.

As stated in a previous section, contrary to my own expectations of more consistently passionate narratives, I discovered that there were more nuanced distinctions in reasoning for membership to the board. One of the Chairs I spoke with told me, "You know, to say people who sit on the board come because they're cheerleaders for research universally, I don't think is actually correct" (B2). While most are motivated to "serve" or

"volunteer" on the board, others may have subjective bias or a focus outside of protecting human subjects. This is not an indication of whether or not they are ethical people, just that their ethics are valued differently than the institution's. While individuals may be obligated to certain moral registers over others, there is still a basis of empathetic consideration throughout all ethical foundations.

If it is this difficult to characterize an ethical person based on their fragmented morality, perhaps it is better to consider the commonalities of ethical places. If ethical people are not intuitively drawn to these positions, are the authoritative circumstances truly what make them ethical? Should we not expect our representatives to be ethical, and if not, then guarantee there be structures in place to assure it?

**The Enculturation of Empathy in Ethics**

In attempting to understand why people may join positions of representative power like the IRB, I assumed that membership rested on the fact that volunteers wanted to be there to ensure the protection of human subjects in research, first and foremost. To my surprise, there were various reasons for joining and remaining on the board, some not even wanting to be there at all. One member spoke of their membership like an invitation into an unfamiliar realm:

> "I was sort of looking for a new challenge. You know, it was time to try something new, and I met some folks at a local conference from BMC who were involved with the IRB and they were looking to recruit additional folks, primarily community members. So, I spoke with them, and they asked me if I'd be

interested, and I said, ‘sure’, and they contacted the Director who then contacted me and we met for a couple hours and he offered me a seat at the Panel” (G1).

In comparison to this lay member, a lot of the scientific or medical professionals that I spoke with who had previous knowledge of the IRB were research-based and often had negative understandings that led them to wanting to learn more about the process. For example, and like many other recruitment stories I heard, one member said, “I attended some kind of informational event about the IRB. I guess I should say, before that, you know, I had been involved in many studies and we always had to get IRB approval, which included local IRB, you know, our BU IRB, but also IRBs at hospitals and so on,” (O2). As this member amply put, investigators often have laborious communication with the IRB in order to get a study submitted for institutional approval. “So, it was always a part of the process, and I would say it was a fairly *onerous* part of the process. So, like many researchers, I consider the IRB as kind of a pain (*laughs*),” (O2).

Most of the medically affiliated members I spoke with actually considered their membership as an obligation of service to the overarching biomedical institution and considered their priorities to be found elsewhere. “As far as how I got into the IRB, I was basically asked by my department chair. (*Pauses*) And I—honestly I fought it, but I-I lost (*laughs*). So, I'm on the IRB! Like, it's my community service as my uh, as my department” (G2).

Though each individual has relative priorities and concerns, one distinctive theme I noticed throughout this project was the consistent sense of *duty*, or moral obligation to

protect subjects. This is further evident in the members who do not necessarily want to be there because of other priorities (more frequently among intuitionally affiliated members), but regard their membership as somewhat of a chore that *has* to be done. This is another example of different professional priorities and, for that matter, moral registers, a fact also illustrated in the IRB's infrequent recruitment and long membership lengths. One Panel Chair lamented, "Yes, on all levels, I actually strongly encourage people, although it's considered--to be honest, in academic medicine, to be the worst assignment, actually, next to serving on the admissions committee for time, effort, and academic yield, but I think that there can be a great benefit for participation in serving on an IRB" (B1). During the Focus Group of IRB Directors, one participant stated,

> "You know, we've had members in the past, who, you just know that they're just showing up for the lunch, (*chuckles*) I think, or-or because the, the Chair of their department or the Chief of their Divisions said, 'you have to be on the IRB now' and they're like, 'Okay, fine, I'll show up but I'm not going to do anything,' and, you know, they'll always say, 'Oh I agreed with everything the other reviewer said', you know, and that's their statement officially every time, you know, and you kind of know what's going on" (D1).

Among community members, this sort of institutional obligation may not be present, but attendance is still affected if duty calls elsewhere. When asked about what kind of qualities makes a good panel member, one participant joked, "Hmm. Ah, well. I'm, um... I show up? That's number one! That's number one" (G1). Despite participating solely out of some mandated institutional requirement, it is obvious that the role is taken

seriously nonetheless. The duty to protect subjects, or vulnerable people, is still there. One participant profoundly articulated the conflicting obligations:

> "I mean, I feel like, you know, there's a real *hierarchy* in medicine—it's unspoken, but as a newbie, it's hard to raise your voice and so, I don't, I don't—I mean, I *did* say something with that that that biopsy study, and I *did* say something with the blood pressure cuff study, both—you know, both comments were to the effect, I mean, of what I expressed to you that I was worried about. You know, low income people being preyed upon by these researchers, um… And people were sort of like "Eh", you know (*laughs*), there wasn't a lot of discussion about it—it didn't… it kind of fell flat. And so, I'm not—I mean, I could devote myself to reforming the IRB system from within, but *I'm not going to do that*, because I think that there are more important causes on which to spend my time. Because I think the world—the world is a difficult place and needs a lot of help in all sorts of ways" (G2).

Weighing such obligations is the foundation of moral reasoning and empathetic decision-making. It also demonstrates the uneasy tension between conflicting and co-existent moral registers. Representative institutions like the IRB provide a framework and process for collective ethics and the enculturation of empathy, but it is clearly not the only setting in which morality or moral reasoning operates for the individual.

As stated earlier, moral reasoning is inherently mandated by the institutional ethics first put forth in the Belmont Report. By requiring and practicing empathetic consideration toward the anonymous research subject, the IRB enculturates empathy on

an institutional level. In the bioethical determination of value to an anonymous subject, empathy becomes necessary to understand and weigh subjective experiences. If someone is not capable of such empathetic consideration, it would be sensible to ask how they came to the representative position in the first place. Other representative bodies may also practice such empathetic decision-making when considering the "greater good" for different *categories* of people. Following these practices of empathetic consideration, ethical pluralism can be deployed as a way of enculturating empathy through the abstract representation of equal and incomparable moral registers.

Asking someone to be an ethical representation of a community or institution is unfair and more importantly, *unrealistic*. It is, by my definition, impossible. Our collective understanding of the world and its layered meaning is both a conglomerate history and the acknowledgement of an unimaginable future. To debate things for "the greater good" of biomedicine, or humankind, is to make a value judgement based on a collective understanding that we cannot possibly conceive. Rather, we must ensure that places of ethical decision-making have the tools to render more considerate, ethical people.

Empathy provides the abstract conception of value in distinct, pluralistic experiences. Using the anthropological understanding of a categorical axiology, empathetic consideration is understood as a way of conceptually re-orientating the self and other with layers of meaning based on subjective experiences. This process of narrative thought influences reasoning, decision-making, and the perpetuation of culturally bound ethics. Thus, ethical pluralism and similar anthropological theories of

collective, evaluative knowledge have the capability to enculturate empathy as an obligation on a societal level.

## CHAPTER SIX: THE CULTURE OF HOPE IN BIOMEDICINE

*"I believe part of my role as a physician, as a biomedical researcher is to... I think you have to believe positively in research--that research can, when done ethically--can advance, you know, the human condition--can lead to important changes, and I think that's important"* (*B1*).

Most of the Panel Members I spoke with shared a similar sentiment of their faith in scientific research. Whether practicing researchers themselves, or someone who participated and had a positive subject experience, they shared the general consensus of biomedical research being done for good. This intrinsic, positive association with medicine is further evident in the analysis of the "therapeutic misconception" and its relationship with the "medical imaginary". Thinking back to the Belmont Principles and specifically the value of "beneficence," the concept of "do no harm" is well ingrained in research and medical ethics, influencing decision-making both on the part of the physician, and the patient seeking care.

### The Therapeutic Misconception

Why do potential subjects join research? Will the study directly benefit them? If not, will it lead to an increased understanding of the disease or problem? Is it some unspoken *duty* to fulfill to science and humanity? If we take any kind of compensation out of it, people join research studies for a myriad of reasons. Recruiting for biomedical

research then depends on whether individuals seek them out or coincidentally become part of the target research population.

The problem of the "therapeutic misconception" comes from the already complicated concept of informed consent. To ethically participate in research, a subject must fully comprehend and consent to a study's design. The therapeutic misconception poses a larger problem for a subject's understanding of biomedical research in general. It is the idea that medical and health research must inherently be therapeutic in its purpose and will therefore provide aid for the research subject in some way. Further, "The therapeutic misconception occurs when a research subject fails to appreciate the distinction between the imperatives of clinical research and of ordinary treatment, and therefore inaccurately attributes therapeutic intent to research procedures" (Lidz and Applebaum 2002, 55).

This therapeutic bias begins with a subject/patient's relationship with their doctor. We generally go to medical professionals to receive care, so if something experimental is offered, why would we consider it differently? "Indeed, subjects have difficulty believing that physicians and other health care professionals would ever do anything that was not intended to be directly beneficial to them. Thus, many potential research subjects enter the consent transaction with a strong therapeutic bias" (Lidz and Applebaum 2002, 57). This bias is not unfounded. They are not, or *should* not, be wrong--Why would a physician offer a research study to someone unless it provided them benefit?

Biomedicine promises to "do no harm," above all else. Even in experimental research, the proposed benefit must outweigh the risk of subject harm to gain IRB

approval. As one member stated, “I mean, it's our job to balance risks and benefits. So, if there are risks to privacy, or if there are physical risks from participating... the question is, do the benefits, either to the individual or to medical knowledge, or to society, outweigh the risks?” (O2). There are multiple layers of institutional bureaucracy to ensure that studies are consistent in protecting human subjects and promoting purposeful research, but sometimes harm still occurs. Knowing this, there is little reason for patients to become research subjects without the notion of hope in a therapeutic outcome. The therapeutic misconception allows for this dynamic to promote the participation in research at all.

Without a subject’s belief in a beneficial outcome, their reasoning for being in research would have to be found outside of a *patient*’s understanding. If recruited by someone other than their doctor, their reasoning for participating might relate more to compensation or general sense of duty. But by recruiting *patients* to be subjects, research may always be understood with a therapeutic bias. If the goal of experimental research is to advance medicine and science, it should retain such therapeutic aims.

One of the community members I spoke with talked very positively about experimental medicine, but later stated: “You know, a lot of patients, they talk about clinical trials as sort of being their "Hail Mary Pass," right? ‘*This is a shot that I've got to get better.*’ What I feel like I see a lot of times, with clinical trials, is that that is not the case,” (G1). This member empathized that they also received ongoing care for something without a cure. They continued,

> "You know, a lot of clinical trials it's really stated upfront, that this is not going to be of direct benefit to you, this is going to be for research, and maybe someday someone with your condition is going to be able to get better because of what you're doing now, or we're going to learn more about the disease... but I think *a lot* of patients, maybe their physicians, talk to them in this way or whatever, but they think this is *it*, this is *going to help me get better*." (G1)

This therapeutic misconception is two-sided in its formulation and further perpetuation. A subject would not be naïve for wanting to participate in research solely because of the *potential* benefit, but they must also have a complete understanding of the study and any potential risks in order to offer informed consent. Patients recruited for specific reasons are often prompted by persuasion or desperation because of the perception of no other options, something medical professionals are fully aware of as well. Doctors should always consider experimental research with any proven comparative therapies, but they are often influenced by countless other external factors and personal priorities. Further, medical professionals are influenced by the pressure to produce good, innovative biomedicine. This inherent push for better treatments and ever-expanding knowledge within biomedicine is what maintains the other side of the therapeutic misconception; the medical imaginary.

**Enthusiasm for Science: The Medical and Technological Imaginary**

Contributing to the book, *Subjectivity: Ethnographic Investigations*, medical anthropologist Mary-Jo Delvecchio Good explains the "culture of hope" underlying

biomedicine using four interpretive concepts: "the medical imaginary, the biotechnical embrace, the political economy of hope, and the clinical narrative" (Good, 2007, 364).

Rather succinctly, Good defines the medical imaginary as, "that which energizes medicine and makes it a fun and intriguing enterprise," later adding, "and those who suffer serious illness become particularly susceptible to hope engendered by the cultural power of the medical imagination," (Good 2007, 364). She states that such relationships between medical science and patient populations can be traced in financial trends and even political regimes over time. More specifically, she denotes an enthusiasm in American biomedicine, or "the many-possibility enterprise" that further influences a larger, global medical imaginary. "Enthusiasm for medicine's possibilities arises not necessarily from material products with therapeutic efficacy but through the production of ideas with potential but as-yet-unproven therapeutic efficacy" (Good 2007, 364).

This "production of ideas with potential" constitutes the recruitment strategy of biomedical research. It is the belief in better science being possible, and this possibility being infinite. In other words, the medical imaginary is the overarching belief in potential innovations and technology that engender hope within scientific medicine. The imminent discoveries and possibilities within an expanding medical knowledge create a sense of optimism in the larger clinical narrative for both patients and physicians. This phenomenon has thus developed a "Political Economy of Hope," in which institutions, organizations, and governments may take advantage of wagering potential therapies with hope (Good, 2007).

Following Good's argument, the complex *mechanism* of medical science is highly interdependent with the modern growth of technology and its relationship to health. Defining this "biotechnical" relationship, Good states, "The concept of 'embrace' conjured the subjective experiences and affective responses of many clinicians and their patients when using new biotechnologies, high-technology experimental treatments, and even salvage therapies" (Good 2007, 367). The subjective understanding of this inflated association between developing technology and medicine is therefore further influenced by an underlying hope in technological solutions. Beyond its existence and influence within the medical imaginary, there is likely a "technological imaginary" in itself that could be further theorized and explored.

She concludes that this *enthusiasm* for the development of technology "*sparks* the medical imagination and drives the political economy of hope, as well as our society's investment in medical adventures and misadventures," (Good, 2007, 367). Though she claims this enthusiasm may be characteristically biomedical (and American), she again situates the concept as a globally interacting and enculturating phenomenon. "Among my American medical colleagues are those who acknowledge the phenomenon, are energized by enthusiasm albeit tempered with irony, and recognize when patients are embraced" (Good 2007, 367).

In my own research with Panel Members and researching clinicians, I also noticed this enthusiasm for science. In addition to the quote from the beginning of this chapter, many members that I spoke with were able to articulate this feeling and connect it with their intended purpose and decision-making practices on the board. One researcher and

"scientist-member" elaborated that this excitement may be why unethical research can still sometimes happen.

> "I would say the vast majority of unethical happens because of a lack of education and excitement about the science. I think sometimes someone just happens to see something that they feel is amazing and so they move forward, not fully thinking through the ramifications of what that means for the patient-subjects or uh--the subjects themselves" (O3). They continued:
>
> "And so, enthusiasm in science is an amazing trait to have in somebody--I see why it happens, it's just important for the education to be there so that way they can recognize, because virtually anything is possible. And I would say that the vast majority of humanity wants to participate in scientific research, to some extent" (O3).

The enthusiasm this researcher describes is tangible. They smile as they matter-of-factly state, "*virtually anything is possible,*" and their wide-eyed excitement is contagious. Does the vast majority of humanity want to *participate* in scientific research? I might argue otherwise, but think they may be on to something. This is where the therapeutic misconception can come into play between patients and researchers. Perhaps the *desire* to participate in science, and relative enthusiasm, has more to do with knowledge acquisition than anything? While I have found a consistent sense of *duty* to be here, most people (and especially patients), have more pressing personal priorities.

**The Clinical Narrative: What Pressure?**

While the enthusiasm for the possibilities of scientific research may "spark" the medical imagination, innovative technology is usually rather founded in necessity.

One of the members I spoke with asserted, "I think my own personal perspective has been that you can have all the regulatory paperwork, but if someone's going to be an unethical researcher, not an ethical researcher--it's going to be--they're going to *do it*, right?" They expressively continue: "I mean, they're going to, and it may be very difficult to identify or monitor that. So, you do have to start with a fundamental trust that the *reason* why people are doing research is for a societal benefit and that they are trying to *improve*… you know, fundamentally…" (B1). Echoing the same sentiment as the quote from the start of the chapter, this member expertly expounds that ethical research begins with a cohesive and fundamental belief in the purpose of bettering humanity.

Good explains the "clinical narrative" drawing from previous anthropological work with narrative thinking (Mattingly 1994 & 1998) and their own past experiences with oncology patients navigating lengthy, often complex relationships with their doctors. Within a biomedical context, she states that concepts of narrative analysis "illuminate how affect and desire play out in clinical narratives, seducing patients and clinicians and enveloping both in a world of the medical imagination, with a many-possibility regime of truth and with fantastic but apparently purposeful technical acts" (Good 2007, 268).

Specifically, narrative analysis of subjective clinical experiences allows for the deconstruction of individual realities and exemplifies the framework of urgency and purpose constituting the medical imagination. We use narrative analysis to "plot" a

coherent and logical treatment experience and turn it into a story that makes sense. Why would someone join experimental research? Well, because they have tried everything else, of course. Why would a clinician offer a patient some study without benefit? Perhaps they need more 'subjects' to meet an institutional requirement.

In comparison to Panel Members, IRB analysts have a much more intimate understanding of the federal regulations and institutional oversight that may identify as potential "problems". When asking an IRB analyst about why they thought unethical research still happened, they laughed a little uncomfortably and said, "Um, I think, you know, I think, very rarely you have people that are doing sort of *willful* misconduct--sort of out to, maybe, you know, take advantage of subjects or, data falsification or things like that" (A1). In contrast to the response I received from the previous member, they state:

> "I think most of it stems from the fact that, you know, research is *in addition to*, I think, you know, clinical duties and people's jobs. So, people are balancing a lot, and I think that, you know, researchers on a whole might not have as intimate an understanding of regulations and ethics as we do, and so a lot of it, a lot of any misconduct or mistakes just stems from not really understanding fully about how to do something. I think very rarely, it comes down to, you know, actual willful misconduct" (A1).

Using Good's clinical narrative, it is important to contextualize and make sense of why someone would engage in something deemed as unethical research, both on the part of the subject and researching clinician. To exemplify this, I will discuss how the analytical theme of an uncharacterizable "pressure" consistently came up in this research. When

asking a medical doctor and panel member why they thought unethical research happened, they replied, “I would say… There's all kinds—I mean you can't give a single answer to that because I think in all kinds of different scenarios, there's *all* sorts of drivers of that,” they laugh, continuing:

> “But, um… one common reason, I'm guessing is that, […] you *know* something is going to necessarily be a little unpleasant, the scientist feels that it's worth doing, and then they compensate people, but it's a more economically vulnerable that might engage, you know, be more willing to engage because they need… (*louder*) *the money*, so that's… one reason” (G2).

They pause and start again:

> “Um… Another reason, like in coronavirus, uh, like the situation with COVID, you know (*their voice drops*), it's just, there's all so much *pressure* to get something done,” their voice lowers again, almost whispering, ”the whole world is waiting for… the vaccine or for, you know, drugs that are effective, and so it's… there’s this *pressure* (*quickly*)--there's pressure to the point that people cut corners,” (G2).

This interview took place in June of 2020.

**The Pressure of COVID-19**

My research began with attending my first IRB Panel Meeting in November of 2019. Between November and April of 2020, I completed a Service Learning Internship

in collaboration with my graduate program and university IRB. Though my official research did not begin until the summer of 2020, I was able to experience and observe the onset of the COVID-19 pandemic in a biomedical context and among individuals tasked with the ethical decision-making on the forefront of experimental research. Boston was one of the first major urban areas in America to see the devastating effects of COVID-19, and living through it is here something I will never forget.

The first mention I have of the virus in my notes is from the in-person meeting on March 5th 2020. Simply, "*Coronavirus talk before meeting starts,*" and a later inquiry about the lower attendance being related (*5 March 2020, Blue*). The way "Coronavirus" is written in my notes looks foreign and distinct, like a word I was still trying to learn.

The next entry in my journal is for March 19th 2020, with a paragraph at the top of the page stating, "*COVID-19, or the coronavirus, has caused BU and affiliated research to be shut down. Social distancing and quarantine procedures cause remote panel meetings via conference call," (19 March 2020, Green).* I remember being nervous, but I was determined to act professional. I was hopeful to hear some more information from the medical professionals on the board because at this point, I was terrified. I called in and was beeped through immediately, taking note that it sounded like half of the people in attendance were still in-person. I write, "*Not sure how some people are still allowed there? Will try to figure out who/why? Seems like by importance," (19 March 2020, Green).* I realize later that this is likely the medical doctors that the quarantine would not apply to. There are technical difficulties that cause increasing frustration and it becomes

clear that the conference call is not the best technique for group discussion. Out of necessity, Zoom's innovation and professional incorporation does not take long.

While I had already begun to notice a general sense of time constraint, this specific meeting felt much more hurried—and tense—than the others I had attended. All of the meetings began at noon and the latest they would ever run is 2:00PM. If a study review took too long or any time was wasted on less important discussions, an IRB analyst or Panel Chair may urge people to get back on track. The entire meeting is also recorded in "Minutes" by an IRB Member that details every motion, critical engagement, and all comings and goings. I noticed many members have to leave the meeting after their specific presentation or review, often having to leave in order to make it to some other appointment or clinical duty.

The next Panel Meeting, and the remainder of the Panel Meetings observed for this research, take place on 'Zoom,' the video conference application. While some people have started to set up 'home offices,' it is clear that there are some members still working from BMC. The Chairs urge members to review things diligently, but quickly so that we can all "*get on with it*" (26 March 2020, Blue).

The next meeting is started before all members can get there. I'm not even sure if quorum was reached. Everything feels rushed. Everyone is on edge. This week, the United States begins to lead the world in confirmed cases, and worldwide cases hit 1 million (NYT Timeline). One of the Chairs, a specialist in pediatric infectious disease makes the remark, *"I'm sorry for a lot of things these days,"* and makes it clear that they must get back to work (9 April 2020, Green).

I found through interviewing subjects and particularly in experiencing this pandemic within a research context, there were often more pressing and sometimes conflicting commitments that made it difficult to prioritize being an institutional Panel Member. The subsequent pressure that occurred with the onset of the COVID-19 pandemic downplayed certain moral registers while dramatically highlighting others. In experiencing this "moral breakdown" and cultural crisis within the heavily controlled environment of the IRB, I recognized the reality of ethical pluralism and a reorientation of ethical understandings and enculturation in altered and shifting social conditions.

Outside of the designated "community member" role, members are often medical doctors, hospital affiliated staff, or clinical researchers who were familiar with the IRB in some regard when they were recruited. As one community member put it:

> "I think that, the people on the IRB, especially the medical professionals--I've sensed that each one of them is really passionate about being involved in that, and I'm not exactly sure how folks get recruited to the IRB from within the institution--I don't think it's mandatory, I think it's people who *want* to do it. So, you get these very brilliant people who are willing to invest their time and their intelligence in, you know, challenging what could easily be a steamroller or a rubber stamp and we're super lucky" (G1).

As this individual points out, their membership in the IRB is voluntary, meaning that they choose to be there and are likely not compensated in any way for their time (the Chairs and Co-Chairs of each Panel are funded). Beyond being privy to the other side of the research process, I was surprised to find that there is not much benefit to being a Panel

Member. Nevertheless, almost every member with whom I spoke to was extremely dedicated to the work and expressed that they enjoyed providing their contribution to the board—even the individuals who regarded their membership as a chore. While it can be hard recruit and keep new members, the ones that show up consistently do, often being members for multiple years. So, without compensation, why show up? Where does this sense of obligation, or *duty*, come from? Is it a merely a commitment to the institution? Or are certain individuals compelled to make the world a better place, however they see fit?

Despite having diverse priorities of their own, each Panel Member regarded their position on the board to be important, sometimes wagering personal and professional priorities with the influence of their attendance and vote. While ethics boards and other representative bodies have an obligation to try to accurately reflect their affected populations, IRBs have to first consist of scientific experts in order to understand and approve biomedical research. This positionality and related power is also the source of the 'pressure' that researchers and clinicians often express. By interpreting bioethics, and further by investigating and enculturating the subjective understandings of the medical imaginary, the IRB serves as a mechanism of moral authority in biomedicine.

# CONCLUSION

## An Anthropology of Ethics

The question of ethics begins and ends with how we should treat one another. It is the metaphysical golden rule. It is the origin of religions and language, concepts of fairness, justice, and propels the human imagination by what could be possible if only we had adequate resources and a common understanding of one another.

Anthropology attempts to help the latter, but as elaborated on in the fourth chapter, this categorical axiology constructs more problems of its own. Attempting to categorize and understand different "types" of people innately questions how we should come to understand and engage with people who seem different from ourselves. The question of ethics is therefore latent in anthropological thought, something many anthropologists are now contemplating in modern societal understandings of morality and globalization. (See recent citations from Laidlaw 2002; Haidt 2008; Keane 2016; Mattingly and Throop 2018; etc).

In determining how we should treat one another, the first thing that must be defined is what constitutes life; what makes a human being? Again, something that has been historically difficult to agree upon, but there is *some* abstract consensus. What exactly *is* life? We can say, across cultural understandings, there is a recognized beginning and an end--Where does it begin and end? This is even more fundamentally contested. But, if we can come to a consensual definition of life, even abstractly, as an experience that varies by personal circumstance and is subsequently experienced through a body that determines the experience as well, we may begin to ask of our obligations to

different experiences. Do we have any obligation to create *good* life experiences for others? An obligation to an equality of experience? Or are we only obligated to our 'selves' and our experience? These are the same questions that have driven collective wonder in philosophers, scientists, and decision-makers for ages. It is the heart of Kant's categorical imperative: the golden rule—the question of how we should treat one another.

In the fourth chapter of this thesis, I have proposed the definition of *ethical pluralism* in an attempt to help with this abstract articulation of nondescript values that we can assume equivocally belongs to all. This notion of ethics has always been intuitive in anthropological thought—we each name, value, and understand reality differently depending on our culture. My hope is that this concept may continue to build a bridge between anthropology and other interdisciplinary studies of morality. In this construction of ethical thought, anthropology's categorical axiology serves evaluative and expanding theory in subsequent relation to an ever more globalized and interacting world.

Anthropology asks people to consider themselves within the larger world around them. It asks for positionality and consideration of others in relation to oneself. Indirectly, it is thus a way of inscribing moral considerations. By requiring insight into other worldviews and lived experiences, anthropology can thereby enculturate its own researchers and students into empathy, and into empathetic thinking as an ethical value in modern societies.

Empathy is intuitive for some but, interestingly not for all. On the one hand, it is an innately human emotion that comes from the evolutionary necessity to cooperate, but it is also an incredibly hard thing to measure (See Michael Tomasello, 2014). Further

research needs to be done on this phenomenon to explore its biological connections. Beyond its evolutionary lineage, however, empathetic decision-making is also culturally influenced. In places of representational authority, in which a representative body makes the best decisions for the general population, it is employed as a form of narrative and moral thinking to aid in ethical decision-making. Cultural and personal experiences influence this narrative reasoning, in which empathy implies the ability to value others as someone *like* you. It is a necessary standard in representational decision-making as is demonstrated in Institutional Review Boards, societal judicial decisions, and any position of moral authority.

Throughout the fieldwork of this thesis, situations of ethical decision-making were encountered during Panel Meetings of the Institutional Review Board tasked with representational authority and various perspectives of biomedical expertise. As illustrated in the experiences of both myself and the subjects of this research, the COVID-19 pandemic provided another layer of ethical phenomena to analyze in regard to prioritizing different values by culturally dependent names. In an even more specific demonstration of moral ambiguity and progression, I would like to discuss the murder of George Floyd and its cultural ramifications.

**The Quarantine Summer Experiment**

There are a few perfect circumstances occurring at once to make the contextual details of this abhorrent violence such a dynamic and attentive moment in modern history. As noted previously, the COVID-19 pandemic took hold of the United States

publicly (and only initially thought) in early March of 2020. Boston, where this research has taken place, was one of the first hard hit. I remember still convincing friends back home in Texas to take this seriously before it even made a blip in the southwest.

On March 11th, the WHO declares COVID-19 a pandemic and by March 19th, California issues its first statewide stay-at-home order (AJMC COVID Timeline). The following months are hard to describe now--It was filled with anxious anguish. As elaborated upon in previous chapters, the Panel Members that I interacted with often had to make even more difficult decisions in weighing their medical, research, and personal priorities under intensifying pressure. As the world desperately waited for answers to come out of the biomedical community, our attention was captured by something more pressing.

On May 25th, 2020, 46-year-old George Floyd attempted to purchase a pack of cigarettes from a local convenience store in Minneapolis, Michigan. As reported in BBC news, "Mr. Floyd had been living in Minneapolis for several years after moving there from his native Houston, Texas. He had recently been working as a bouncer in the city but, like millions of other Americans, was left jobless by the coronavirus pandemic" (BBC Timeline).

Though there is little to no report of how it was determined, the teenage employee was suspicious of the $20 bill Floyd used to pay and asked for the cigarettes back. When Floyd refused, the young store employee called the police. In the call transcript later released by authorities, "The employee said the man appeared 'drunk' and 'not in control

of himself,'" (BBC Timeline). When police arrive at the scene and approach Floyd's car, he apologizes repeatedly.

One of the officers decides to pull him from the vehicle because he is not being cooperative. "Mr. Lane asks Mr. Floyd to show his hands at least 10 times before ordering him to get out of the vehicle," and for some unknown reason, the officers' guns are already drawn. At this point, a struggle ensues, recorded by both police body cameras and various bystanders with smart phones (BBC Timeline).

What happens next is a moment of decision-making. On the part of police, perhaps acting according to procedure or how they best assessed the potential escalation of the situation. On the part of Mr. Floyd, perhaps inebriated (though nothing is ever proven) and rightfully scared for his life as a Black man in police custody. Over a counterfeit $20 bill. Over a pack of cigarettes, and during a worldwide pandemic and nationwide economic shutdown.

Officer Derek Chauvin approached Mr. Floyd, who now laid face-down on the ground with his hands cuffed behind his back. After attempting to usher him into the police vehicle unsuccessfully again, Derek Chauvin crouches down and places his left knee "between [Floyd's] head and his neck" (BBC Timeline). He then kneels on his neck for 7 minutes and 46 seconds, killing him as he repeatedly plead for his life.

The video is traumatic if not barbaric—and it is shown on most morning news stations the next day.

While George Floyd's death is deemed a supposed horrible accident, the public response is a visceral and lasting outcry. How could this happen? Could this possibly

happen to *me*? As stated prior, there were many things that took place to make this phenomenon happen, but most notably so was the national quarantine causing most working individuals to be at home and more vehemently aware of current events--We all saw the video on the news. It was hard to miss it or not be outraged by it. The fact that it was recorded at all probably also had something to do with people not being at work or on their normal schedules.

Almost instantly, the video of this man's murder was circulated and deemed a horrible, wrong decision on the part of the police. While some of us felt this intuitively, others may wait for morality, or notions or what is right and wrong, to become more ethically structured and culturally enforced. The same is true in all pluralistic ideas and complex societies. Namely, enculturation works on many levels and leads to the amalgamation of truths through constant evaluation and comparison.

By the next day and following week, riots began to ripple and then steadily erupt across the United States. Even amid the raging pandemic, people took to the streets in masks to march and protest against the exceptional police brutality of Black people and in George Floyd's name.

It felt like something changed here. Something was different this time. Unfortunately, this was not the first time, even recently, that Black people had been killed by the police for no lawful or ethical reason. So, what changed? That it was recorded? Was it just the fact that more people were watching? I argue so.

The power of influence in groups is strong and innately human. We are evolutionarily wired to cooperate. When someone with authority deems something right

or wrong, we listen. So, can we trust these powerful people to make the right decisions? Most of the time, it seems. There are structures in place to keep 'bad' people from powerful positions. But, what happens when they still manage to get there? (See everything from Nuremburg to Trump administration). Someone with authority calls it 'bad,' and we change.

Maybe it just takes enough people paying attention. Maybe it takes the *right* people. But somewhere along the way, someone decides what *feels* right and wrong and moralizes whatever action or phenomenon it may be by adding a subjective perspective to it. Ideas move—and movements happen—the cultural perspective changes when it pluralizes. Ethics are created out of this retrospective consensus.

**The Problem of Ethics: Reflexivity (Self-Awareness) in Moral Authority**

On May 28th, I attend a Panel Blue meeting. I take scratch fieldnotes of different comments on "how surreal things feel" pertaining to COVID and Zoom. I notice that almost everyone has their camera turned on today (which was rare)! I write, "Most people are dressed in work clothes even though it is nearly eighty degrees outside (B4 is the exception in a tank top)" (Panel Blue, May 28th 2020).

There are a few studies on the agenda for the day, each taking at least 15 minutes of review to go over a study summary and any flagged protocol from the IRB analysts. This is usually followed by expert discussion before a vote is taken. Though a cardiac study may be assigned to a cardiologist for particular review, someone else on the board

is encouraged to offer other expertise or bring up specific experiences to help inform other aspects of the research.

One of the Panel "community members" takes their turn to discuss a study that has been ongoing for a few years. This specific study was brought to the board because of its targeted recruitment of subjects for diversity. In other words, although I cannot discuss what the study was about, it was attempting to recruit POC specifically. Though this may make sense for numerous medical or research reasons, I was abruptly made painstakingly aware of the squares of white faces staring back at me. There is no requirement for race on the board, only that it accurately represents the surrounding medical research community. While there was not a single POC on the board to comment on their experience, there was a visiting PI who seemed to identify as Black. I note that they look "*extremely distressed*" with this discussion (Panel Blue, May 28th, 2020). Perhaps this conclusion reflected my own uncomfortableness, but an analyst breaks the tension with announcing some personal news and I note that the chair reads the confidentiality statement another three times (Panel Blue, May 28th, 2020). Later and coincidentally, I would be able to meet with this PI through my advisor to discuss their experience. They had questions about my research and intentions, but mainly about my experience with the board. Was this demographic of Panel Members normal? Did it ever change? Further, should race be another determining factor for the overall composition of the board? We only spoke briefly, but their questions were poignant and clear. Black people have an experience unlike any other, and George Floyd's death was still fresh on our minds. Why

are only some perspectives given credence here? Further, even if represented, is it possible to incorporate and equally value all perspectives?

Near the end of the summer, one of my final study participants confided:

> "There's, there still feels--it seems to be like the rest of the world where there is some level of patriarchy on the board and there is also a '*preferencing'* of academic knowledge. So, to know something is often, 'there's been a study,' 'it's been published,' 'this is the accepted literature,' which is privileged--that's often privileged over knowledge from survivors, knowledge from doing the work, life experience--whatever that is. And so, that is just the issue everywhere, and combined with the fact that most of the board members who are men, also are white, also have this academic either MD or PhD status. So... sometimes when there are questions, or friendly debates about whether an issue that I bring up is actually valid or not, there's sometimes, there's this tendency to, "well that hasn't been in the literature, you know, the literature I've found was more about this, this and this,"--and I, it can be a really frustrating... (*exasperated, starts again*)."
>
> "You know, I can't get up and start doing my class. I can't start pulling out all of the, I mean you can't see my bookcase, but like—I *know* my shit. But *how* I know it isn't necessarily how others have *valued* what we know. And plus, most of them probably have no experience--personal experience. So a lot of times—" their eyes drift to their watch and they abruptly stop, "oh, how much time do we have?" (B2).

I assure them that I still have plenty of time, but they check their messages and have to go soon. Their phone has been ringing since we started the interview. They continue:

> "So sometimes, just as an example, like, there's been studies on occasion about like Crohn's Disease, or about I don't know, like conditions of the eyes or something, and invariably you get somebody who says, "Well, my daughter has that disease," or "My aunt has that," and then that--they'll say like, "Oh!" So, then everybody looks to that person and really like, *validates* their one personal exposure or experience as really important. So, in a way, it is like, hypocritical. In some ways, it's like, 'well, we don't know' that. But then, with other issues, people are really open to the varied experiences that people have had in their personal life. When I come in as an expert from the hundreds and thousands of many years of survivors that I've learned from and trainings that I've been to--it always seems to be questioned if others have not had that exposure or that experience or that understanding" (B2).

This individual brilliantly articulated the hierarchy of power in academic knowledge. Though narrative thinking and member experiences are referenced as bioethical reasoning, some knowledge trumps—or is validated—by others. Within current institutional frameworks, representation is not enough—it takes some form of authority.

As anthropologist Webb Keane points out, Foucault held that ethics depend on reflexivity: "Thought . . . is what allows one to step back . . . to present [one's conduct] to oneself as an object of thought and to question it as to its meaning, its conditions, and its goals" [1997: 117 Foucault] (Keane 2015, 24). The sharing of knowledge and

experiences in the context of the IRB allows people to make present evaluations about themselves and their actions. While being a place of moral authority, the group consensus through discussion is what holds true authority for change. While reflexivity is necessary to be capable of ethical-reasoning, it is not necessary for someone to considered an ethical person. In other words, though self-awareness is not a precondition for being ethical, it encourages the same empathetic consideration of self and other that ethical reasoning depends on.

If the capability to differentiate and value others is not instilled in child development, there is still an innate human sense to cooperate. Empathy is intuitive—if an individual is not able to evaluate themselves within the world around them, it can be said to likely be due to some psychopathology or neurological deformity—but they can still recognize and follow the rules. In groups delegated with moral authority, enculturation works on a microscale to encourage cooperation, regardless of individual understanding.

By incorporating a paradigm of ethical pluralism, these institutions can ensure empathetic consideration in their decision-making as a structural and secondary mechanism of ethical objectivity. In effect, this does not leave the decision solely up to specific members or experiences of the Board and provides a necessary construction of anthropological insights to ethical decision-making. Further, this construction of empathetic consideration and subjective understanding influences and enculturates empathy at an institutional level. By making it an obligation to society in a

representational context, individuals may develop mechanisms of empathetic thought that is solely culturally based and enforced.

**Globalization and the Internet**

In accepting an ethical pluralism, it must be recognized that globalization has created a platform of gestalt comprehension. In fact, it could be said that collective understanding is the actual goal of globalization. Before societies were connected, these distinct ethical values simultaneously arose in civilizations around the globe. Now, with the influence of growing international relations and the conception of the internet, cultural values are understood universally and quite often, only so. While there are growing sets of silos that create and propagate their own ideas of truth within more quarantined sections of the internet, our biological and cultural need to stay connected has compelled us to put our collective knowledge on a global scale. Therefore, globalization and the increasing access to the internet has brought forth this new plurality of knowledge.

Anthropology is often compared to the metaphor of "the blind men and the elephant" in which all orientations have separate and very different ideas of their perspectives. If we consider these perspectives as plural knowledge, anthropology is about determining the possibility of truth through pluralistic incantations. Our collective, expanding knowledge is the only truth, otherwise it is only relative.

The internet provides a platform for this knowledge, but also for its subversion. It is also a platform of enculturation, making its reach and plethora of unstandardized

information a horribly powerful reality machine. Anthropology must reorient itself to further theorize and investigate the impact of this unregulated technological imagination on the plurality of cultural knowledge and values. In an increasingly connected and "live" reality influenced by social media, ethical phenomena are experienced together. In this constant plurality of perspectives, there is the possibility of truth.

Ethical pluralism entails that ethics can change. Beyond broad notions of good and bad, values take new forms as we grow our collective knowledge or change our current perspective. Ethical pluralism allows for this change and encourages the growth of perspectives from a categorical axiology in order to evaluate them collectively and progressively. Anthropology therefore has the further potential to evaluate ethical trends through time in the hope and construction of an ethical truth to standardize.

That being said, positions of moral authority must understand and enculturate a pluralistic perspective of ethics in order to collectively evaluate and progressively incorporate some shared standard of right and wrong. Using this process, we may begin to enculturate empathetic consideration as a shared value in itself. In modernity, where humans of all cultures and experiences are more and more easily connected through the internet, this anthropological perspective of ethical thought and empathetic practice is the only collective way forward.

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**CURRICULUM VITAE**